

Decision-Making Regarding Risk-Reducing Options in Breast Cancer

Hannah. G. Fielden

University of Liverpool

Supervised by:

Dr. Stephen. L. Brown

Professor Peter Salmon

Dr. Louise Clarke

Submitted in partial fulfillment of the Doctorate in Clinical Psychology, University of
Liverpool

Acknowledgements

With greatest thanks to the women who shared their experiences with me.

Thank you to Stephen Brown, Peter Salmon, Louise Clarke and the wider research team for your help and expertise throughout this process.

With thanks to my family for your ongoing support.

Table of Contents

Contents	Page Number
Introductory Chapter: Thesis Overview	1-2
Chapter 1: Literature Review	3-37
Abstract	4
Introduction	5-9
Method	9-12
Results	13-22
Discussion	22-27
References	28-37
Chapter 2: Empirical Paper	38-68
Abstract	39
Introduction	40-43
Method	44-48
Results	48-55
Discussion	56-60
References	61-67
List of Tables	
Chapter 1: Table 1	13-15
Chapter 2: Table 1	48-49
Appendix 2: Table 1	71-72
Appendix 2: Table 2	73
Appendix 2: Table 3	73
Appendix 2: Table 4	73

Appendix 2: Table 5	73
Appendix 2: Table 6	74
Appendix 2: Table 7	74
Appendix 3: Table 1	76
List of Figures	
Chapter 1: Figure 1	11
Chapter 2: Figure 1	49
Appendices	69-105

Word Count: 22111

Introduction: Thesis Overview

Breast cancer is the most common cancer in the UK and responsible for the second highest number of cancer deaths in women (Cancer Research UK, 2013). Prognostic developments are making it increasingly possible to identify those at increased risk of the disease and advances in cancer risk reduction strategies aim to reduce women's risk of developing breast cancer. However, the risk-reducing strategies available to women have different risk-reducing capabilities and some can have negative side effects. Women at increased risk of breast cancer are faced with a series of complex decisions including whether or not to act to reduce their level of risk, along with the risk and benefits of different risk-reducing options.

Health decision theories afford a central role for risk perception in the uptake of health protection behaviour. To date, there has been mixed evidence for the role of risk perception in the uptake of breast cancer risk-reducing behaviour. Within the quantitative research paradigm, risk perception is often measured as a quantitative estimate, driven by an assumption that women perceive risk in numerical and dimensional terms. This research tells us very little about the forms in which women represent risk and the influence of these risk representations on choices; possibly explaining why studies often show weak relationships between risk perceptions and behaviour. In an effort to further our understanding of women's choices in this area, the literature review aimed to synthesise qualitative literature that explored how women at increased risk of breast cancer perceived risk and the role of risk perceptions in decisions regarding risk-reducing strategies.

Women deemed to be at a significantly increased risk of breast cancer can choose to undertake risk-reducing mastectomy (RRM), the surgical removal of breast tissue for

risk-reducing purposes. This procedure is controversial because of the potential for physical and psychological harm and the mixed evidence regarding the survival benefits. Findings from a case series of women undertaking RRM (Beesley, Holcombe, Brown, & Salmon, 2013) suggest that women were driven to opt for the procedure because of a sense of vulnerability to cancer and desire for cosmesis. These findings call into question the role that risk perception plays in this decision-making process. Conclusions however are limited by the case series design and sparse reflection on the relevance of the findings to theoretical understanding. The empirical study aimed to explore, using in-depth interviews, how women make decisions regarding RRM and to identify implications of the findings for the role of decision support for women considering RRM and for psychological theory.

References

Cancer Research UK. (2013). *Breast Cancer Key Facts*. Retrieved from:

<http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/breast-cancer/cancerstats-key-facts-on-breast-cancer>.

Beesley, H., Holcombe, C., Brown, S. L., & Salmon, P. (2013). Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: Analysis of 60 consecutive cases in a specialist breast unit. *Breast*, 22,179-184. doi:10.1016/j.breast.2012.06.005.

How do Women at Increased Risk of Breast Cancer Perceive and Act on Risk? A

Systematic Review¹

Hannah. G. Fielden

University of Liverpool

¹ To be submitted to the *Health Psychology Review*: Word limit: 30 double-spaced manuscript pages.

Abstract

Options for breast cancer risk reduction are available, but it is unclear how women balance risks of cancer, cancer risk reduction and the risks of side effects. The aim of the review was to understand how women at increased risk of breast cancer understand risk and how their ways of understanding it influence decision-making regarding risk-reducing options. SCOPUS, Web of Knowledge, PsychINFO and Medline electronic databases were searched for published empirical papers. English language, qualitative studies that explored risk perception in adult women at increased risk of breast cancer were included. The 14 included studies were assessed for quality using the CASP assessment tool and presented in a narrative synthesis. Women largely did not see risk in dimensional terms, but were more likely to report categorical representation of risk. Most commonly, risk was perceived in emotional terms and was sometimes defined by family experience. Women reported that emotional representations of risk were most strongly associated with decision-making. These findings question the assumptions of utility models of decision-making that emphasise considered and logical understandings of risk. Implications of this are that the conceptualisation of what constitutes ‘good’ decision-making about risk will need to be questioned in the light of how women actually do make decisions.

Keywords: Breast cancer, risk reduction, risk perception, qualitative, systematic review

**How do Women at Increased Risk of Breast Cancer Perceive and Act on Risk? A
Systematic Review**

Breast cancer is the most commonly diagnosed cancer in the United Kingdom (Cancer Research UK [CRUK], 2013) and causes the second highest number of cancer deaths in women in the UK (Office of National Statistics [ONS], 2012). Diagnosis, treatment and survivorship of the disease can bring a multitude of negative physical, social and psychological consequences (Amir & Ramati, 2002; Bower et al., 2000; Bradley, Bednarek, & Neumark, 2002). Recent advances in prognostic instruments have made it possible to identify women who are at increased risk of breast cancer.

Quantification of this risk allows women to make choices that will reduce their level of risk.

Different options are available to reduce risk of breast cancer but they do so to different degrees and most have side effects. Thus, women considering risk-reducing procedures face complex decisions. These involve balancing their risk of developing breast cancer, against the ability of procedures to reduce this risk, along with the potential for negative side effects. Understanding whether and how they do this involves understanding the forms in which women represent risk and the influence of these risk representations on choices. This review aims to better understand this.

Breast Cancer Risk Factors

The strongest risk factors for breast cancer are age and family history, with the latter largely mediated by specific identifiable gene mutations, such as the BRCA1/2 genes (McPherson, Steel, & Dixon, 2000). Other risk factors include: age of menstruation and menopause, age of first child, (McPherson et al., 2000), diet, alcohol consumption (Ferrero & Namer, 1994) and the use of oral contraception

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

(McPherson et al., 2000). Personal history of breast cancer also significantly increases a woman's risk of developing a new breast cancer (Tuttle, Habermann, Abraham, Emory, & Virnig, 2007).

Genetic mutations in the BRCA 1/2 genes can increase risk of developing breast cancer. Women who carry the genetic mutations and have multiple family members with the disease have an 80-90% lifetime risk of developing breast cancer (Easton, Bishop, Ford, & Crockford, 1993). Certain ethnic groups including Ashkenazi Jewish, Icelandic, Swedish, Hungarian, and French-Canadian have been found to have higher rates of the genetic mutation (National Comprehensive Cancer Network, 2008).

Options Available for Breast Cancer Risk Reduction

Women identified to be at increased risk of breast cancer can choose to access a range of risk-reducing procedures. Radiographic mammograms or more advanced screening through Magnetic Resonance Imaging (MRI) are available for some women (National Institute of Clinical Excellence [NICE], 2013). Screening can promote early detection, which can improve prognosis, but cannot prevent breast cancer.

Mammographic screening also has a high rate of false positives that can often cause distress (Aro, Pilvikki Absetz, van Elderen, van der Ploeg, & van der Kamp, 2000).

Chemoprevention through the provision of Selective Estrogen Receptor Modulators (SERMs), such as Tamoxifen, may be offered to postmenopausal women who are at high risk of developing breast cancer (Bao, Prowell, & Stearns, 2006; NICE, 2013).

Tamoxifen can reduce incidence of estrogen receptive-positive invasive breast cancer by up to 43%, but has no impact upon estrogen receptive-negative breast cancer (Sestak, Cuzick, Evans, & Kwong, 2012). Tamoxifen increases incidence of endometrial cancer and thromboembolic events (Nelson et al., 2009).

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Risk-Reducing Mastectomy (RRM) is the surgical removal of breast tissue, which can reduce breast cancer risk in women at high risk by approximately 90 to 95% (Rebbeck et al., 2004). The procedure can be offered bilaterally (BRRM), the removal of tissue from both breasts, or contralaterally (CRRM) to a breast that has been affected by cancer. RRM is irreversible and is associated with physical difficulties including pain and discomfort (Payne, Biggs, Tran, Borgen, & Massie, 2000) and difficulties relating to appearance and femininity (Hopwood et al., 2000).

Risk-reducing bilateral salpingo-oophorectomy is the surgical removal of the ovaries and fallopian tubes, often offered to women with a BRCA 1/2 mutation. The procedure can reduce the risk of breast cancer by up to 50% (Bradbury & Olopade, 2007) and risk of ovarian cancer by 90-95 % (Domchek & Rebbeck, 2007). However, as with RRM, salpingo-oophorectomy is irreversible and surgery of any kind carries risk of infection and complications. Bilateral salpingo-oophorectomy also produces a premature surgical menopause that will cause infertility and difficulties associated with the menopause (Domchek & Rebbeck, 2007).

Risk Perception and Decision-Making

Risk perception is an individual's personal understanding of risk and is seen as playing a key role in health decision-making (Skinner, Kreuter, Kobrin, & Strecher, 1998). Early health decision-making theories were based on utilitarian principles, whereby people were expected to respond to dimensional perceptions of the likelihood and possible severity of potential outcomes and balance those perceptions with the advantages and disadvantages of remedial actions (Hochbaum, 1958; Rogers, 1975, 1983; Weinstein, 1980,1993). Later views have been based on dual-process models, where heuristic modes of thought exist independently and compete with the

more deliberative modes described above. A number of heuristics have been proposed to play a role in decision-making, the most commonly studied being decisions that involve emotional responses to risk (Leventhal, Brissette, & Leventhal, 2003; Loewenstein, Weber, Hsee, & Welch, 2001; Slovic, Finucane, Peters, & MacGregor, 2002). Later models have abandoned the dual-process approach, portraying risk perception as a function of the idiographic ways in which individuals reduce complex verbatim experiences to simpler meaningful representations (Reyna & Adam, 2003).

Quantitative studies address the questions of how risk is perceived and how it influences decision-making through the prediction of decision outcomes and behaviour from theoretically derived measures of risk (Weinstein et al., 2007).

Decision-making in primary and secondary breast cancer prevention is only weakly predicted by dimensional estimates of outcome likelihood and potential severity (Katapodi, Lee, Facione, & Dodd, 2004; Sivell et al., 2008; van Dijk et al., 2003).

Decision-making also appears to be predicted by subjective states such as anxiety or vulnerability (Howard, Balneaves, & Botorff, 2009; Meiser et al., 2000; van Dijk et al., 2003). Quantitative analyses are, however, limited for two reasons. First, they reflect existing theory and are restricted in the extent to which they can be used to drive future theoretical development, and, second, it is difficult to discriminate between risk perceptions that are central to decision-making and those that are generated in response to researchers' questions (Hawkes & Rowe, 2008).

Qualitative approaches focus on participants' accounts of their experiences and can potentially reveal how women perceive risk and how those perceptions guide their decision-making. The aim of this review was to conduct a synthesis of existing qualitative literature concerning how women with elevated risk for breast cancer

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

perceive this risk and the potential benefits and risks of preventive interventions, and how these perceptions guide decision-making.

The review will aim to answer two questions:

- How do women at increased risk of breast cancer perceive risk?
- What role do risk perceptions play in decisions regarding risk-reducing strategies?

Method

Eligibility Criteria

Studies that qualitatively examined risk perception, defined as women's subjective understandings of risk, were included. Studies were limited to those that included an adult woman sample and specifically addressed future breast cancer risk. Studies needed to state the sample as being at increased risk of breast cancer or identify membership of an established high-risk group. These include women who have established genetic (e.g. BRCA 1/2), or familial (including first degree relatives) risk factors or lifestyle related risk (e.g. overweight) and breast cancer survivors. Studies of women currently under treatment for breast cancer or associated symptoms were excluded. For question two, any methods aimed at risk reduction, including detection and prevention strategies, were included. Inclusion was limited to English language studies. No restrictions were placed on the date studies were published. For quality control, only peer-reviewed published studies were included.

Search

Search terms and alternatives were initially identified using several reviews relevant

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

to this area (Howard et al., 2009; Sivell et al., 2008) and then augmented by initial scoping searches (appendix 2). As the second review question is contingent upon the first question, additional searches were unnecessary. Records of the number of results per search term were recorded (appendix 2 for example).

Search Strategy

Keywords relevant to breast cancer (“breast cancer” OR “breast carcinoma” OR “breast neoplasm”) AND risk perception (“risk perception” OR “risk understanding” OR “perceived risk” OR worry OR dread OR “anticipated emotion” OR “anticipatory emotion” OR emotion* OR vulnerability) AND qualitative methodology (qualitative OR “Grounded Theory” OR IPA OR “Interpretative Phenomenological Analysis” OR “Thematic Analysis” OR “Content analysis” OR “Narrative Analysis” OR “Conversation Analysis” OR “Discourse Analysis” OR interview* OR “focus groups”) were searched.

Information Sources

The electronic databases PsycINFO (1879-2013), Medline (1948-2013), Web of Knowledge (1900-2003), and Scopus (1960-2013) were searched for relevant published literature. References from previous systematic reviews were also reviewed. Searches were combined and duplicates removed before study selection. Hand searches were also conducted of key papers and the reference lists of the included articles.

Study Selection

Using the electronic databases, search terms were identified from titles, abstracts and keywords. Following the search strategy, identified studies were assessed for inclusion. Initially HF screened all identified titles and then the abstracts of selected

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

titles for potential inclusion. Following this, full copies of the studies identified as potentially relevant were read and an assessment of whether they met the inclusion criteria was made. At times when it was unclear whether or not the studies should be included, a second opinion was sought (SB) and a joint decision reached.

Reference lists and reasons for exclusion of studies were kept. Point of exclusion and the reasons for exclusion at each stage were recorded (appendix 2). The process of study selection is presented using the Preferred Reporting Items for Systematic reviews and Meta Analysis ([PRISMA] Moher, Liberati, Tetzlaff, & Altman, 2009) flow diagram in figure 1.

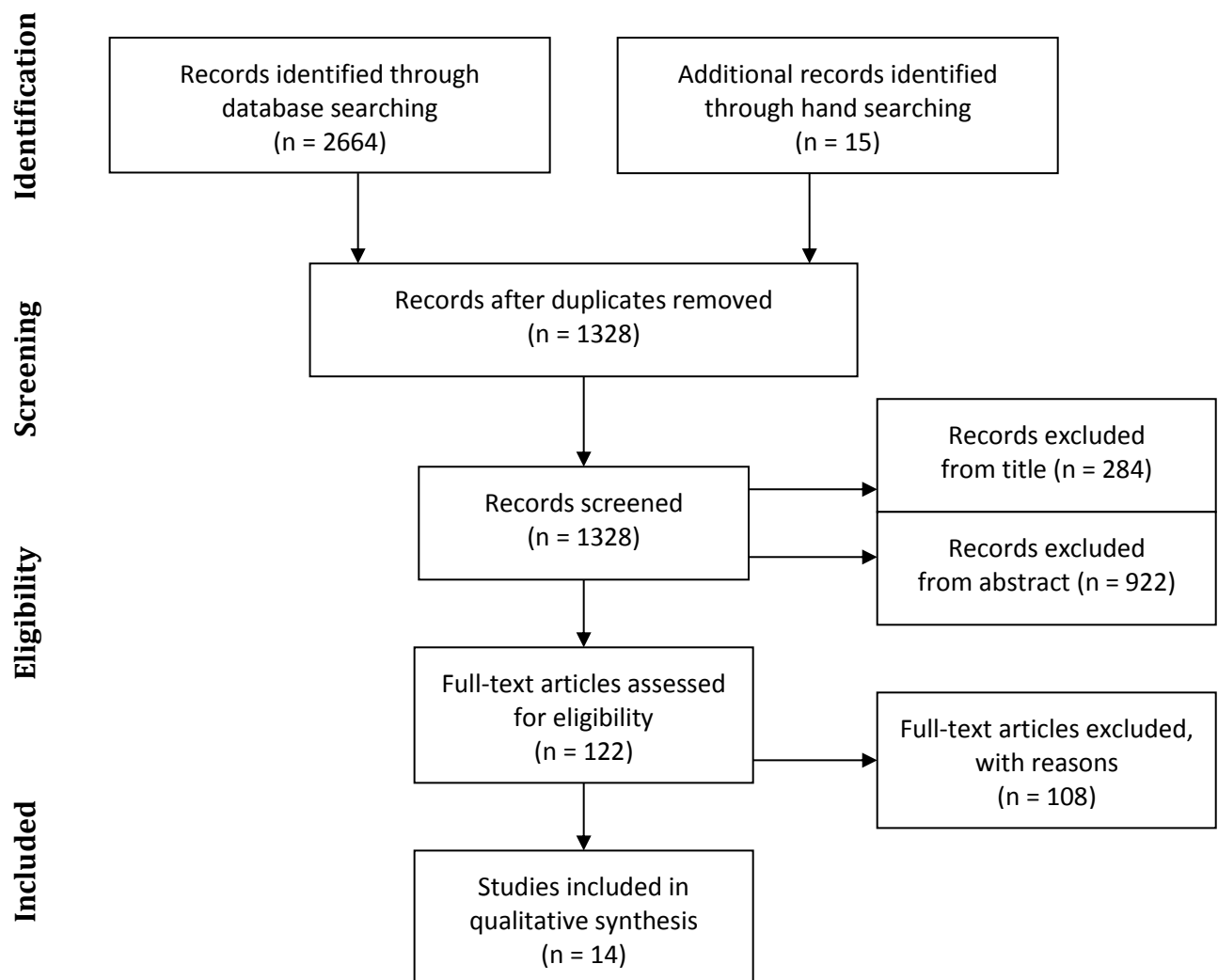


Figure 1. PRISMA flow diagram displaying the article selection process.

Quality Assessment

Although a decision was made not to exclude studies based on quality, the Critical Appraisal Skills Programme (CASP) tool (CASP, 2013) was used to gauge study quality. The CASP for qualitative research provides a quality assessment system based upon conceptual logic and methodological adequacy (CASP, 2013). Studies are evaluated on a ten-point system pertaining to the adequacy of design, sampling, analysis and interpretation (appendix 3).

Data Synthesis

In line with other systematic reviews with similarly interpretative aims (e.g. Sivell et al., 2008) a narrative synthesis was chosen as the method of synthesis. Synthesis was performed at the level of themes reported in the studies, although differing conclusions to the study authors were sometimes drawn in the light of themes from other studies and risk perception theory. To improve the transparency of the process, points 2-4 of Popay et al.'s (2006) recommendations were followed. Specifically, these included developing a preliminary synthesis as a working model, interrogating the model in terms of its consistency and inconsistency with the source data, and reviewing the robustness of the synthesis process itself. The synthesis process was designed to retain the individuality of each study whilst exploring commonalities and contradictory explanations of risk perception and its role in decision-making.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Table 1:

Summary of Included Studies

Reference	Country	Sample characteristic of interest	Sample	Data Collection Method	Analysis	Aim(s)
Altschuler and Somkin (2005)	USA	Eligible for genetic testing (identified as high risk by Gail model) and accepted or declined	n=51 Age: 40-80+ yrs Ethnicity: 93.4% White, 2.5% African American, 2.0% Latina, 2.1% other FH: unclear PH: unclear BRCA: not stated	Semi-structured interview	Grounded theory	Understand why women at similarly high calculated risk, made different choices about whether or not to join a hormonal therapy trial
Beesley, Holcombe, Brown, and Salmon (2013)	UK	Women considered for CRRM	n= 60 Age: 24-68yrs Ethnicity: not stated PH: all FH: not stated BRCA: not stated	Case series	Constant comparative	Understand decision-making in CRRM. (b) Identify factors that influence these decisions
Bennett, Parsons, Brain, and Hood (2010)	UK	Intermediate risk of BC with range of BC worry scores following risk assessment	n=30 Age: 48.1 mean (range not stated) Ethnicity: not stated FH: all PH: not stated BRCA: unknown	Semi-structured interview	Thematic analysis	Understand experience of taking part in risk assessment, (b) living at risk, (c) coping strategies
Chalmers and Thomson (1996)	Canada	FDR with BC	n=55 Age: 20-69yrs Ethnicity: not stated FH: all PH: none BRCA: not stated	Semi-structured interview	Latent content analysis and constant comparison techniques within symbolic interaction framework.	Explore and describe meaning of risk experience in women with FDR with BC

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Dagan and Goldblatt (2009)	Israel	Asymptomatic BRCA 1/2 carriers	n=17 Age: 37-55yrs Ethnicity: Israeli Ashkenazi Jewish PH: none FH: all BRCA: all	Semi-structured interview	Thematic content analysis	How gave meaning to family scripts and dialectic between being concurrently healthy and at high risk for BOC. (b) Ways of coping with risks
Hallowell, Foster, Eeles, Arden-Jones, and Watson (2004)	UK	Treated for BOC and completed genetic testing	n= 30 Age: 39-71yrs Ethnicity: not stated PH: 27 FH: 26 FDR BRCA: 10 positive, 12 inconclusive, 8 awaiting results	Semi-structured interview	Constant comparative	Investigate perceptions and reactions to genetic risks. Establish information and support needs before and after result
Hoskins, Roy, and Greene (2012).	USA	Young BRCA carriers	n=60, Age: 21-36yrs Ethnicity: 3% Hispanic, 97% White, 20% Jewish PH: not stated FH: not stated BRCA: all	Semi-structured telephone interview	Grounded theory	Understanding of lived experiences of women who learn early in life that carry BRCA1/2 mutation. (b) Characterise complex ways BRCA1/2 young women think, behave, and create meaning
Kelly (1980)	USA	Maternal history of BC	n=39 Age: 28-73yrs Ethnicity: 34 White, 3 Oriental, 2 Black PH: none FH: all BRCA: not stated	Semi-structured interview	Grounded theory	Determine needs, concerns, and health practices pertaining to BC. (b) Explore what subjects thought, felt, and did about BC and breast health care
Kenen, Arden-Jones, and Eeles (2003)	UK	FH of BC, do not know if family have genetic risk	n=21 Age: 24-61yrs Ethnicity: not stated PH: none FH: all BRCA: all unknown	Semi-structured interview	Thematic	How healthy women from families with a history breast and ovarian cancer live with their heightened awareness of risk

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Keogh, McClaren, Apicella, and Hooper (2011)	Australia	1 FDR or 2 nd DR diagnosed with BC before 50yrs. BRCA1/ 2 not identified in family	n=24 Age: 35-70yrs Ethnicity: not stated FH: all PH: none BRCA: all unknown	Semi-structured interview	Thematic	Describe (b) how it is related to screening behavior.
Raveis and Pretter (2005)	USA	Caring for mother with BC	n=50. Age: 21-62yrs Ethnicity: 70% White, non-Hispanic, 24% Hispanic 4% Black, non-Hispanic PH: not stated FH: all BRCA: not stated	Semi-structured interview	Content analysis	Understand daughter's experience/ reaction and personal risk and vulnerability following mothers BC diagnosis.
Robertson (2000)	Canada	Attended Breast Health Clinic, aged 30 -50 (pre-menopausal); no PH of BC Only presents data of women indicated to be at increased risk by Gail assessment tool	n=20 Age: 30-50yrs Ethnicity: mostly northern European PH: none FH: not stated BRCA: excluded women who had undertaken gene testing	Semi-structured interview	Thematic	Explore notion of 'phenomenology of risk' to explore women's accounts of their own individual risks for BC
Sheinfeld Gorin and Albert (2003)	USA	At least one close female relative diagnosed with BC	n=26. Age Normalizer 49yrs, Adopter 42yrs (mean) Ethnicity: majority white PH: not stated FH: all BRCA: suggest 'some' but no %	Semi-structured interview	Thematic	Understanding of the effect of risk perception on screening adherence. (b) Explore risk in a woman's natural language
Werner- Lin (2007)	USA	Young age (22-36) BRCA positive	n= 22 Age: 22-36 Ethnicity: White, mixed Eastern/ Western European PH: none FH: 20 BRCA: all	Semi-structured interview	Listening guide	Explore connections between family history and beliefs about susceptibility. (b) Understanding of how family histories/experiences with health care professionals integrated to inform beliefs.

Note. n = number of participants; FH = family history of breast cancer; PH = personal history of breast cancer; BRCA = BReast CAncer gene status; CRRM = contralateral risk reducing mastectomy; BC = breast cancer; FDR= first degree relative; 2nd DR= second degree relative; BOC= breast or ovarian cancer.

Results

Summary of Included Studies

Table 1 summarises the 14 included studies. The studies often defined their sample by shared risk factors and some by statistical risk estimates. Despite women in the samples having similar levels of objective risk, there was great variation in how they discussed risk and the level of emotion they described. This suggests that risk perception and level of emotion is individualised and shaped by more than objective risk estimates.

Results of Quality Assessment

All of the 14 studies included were rated as valuable using the CASP tool (CASP, 2013). However several limitations pertaining to data collection were identified (see appendix 3 for full breakdown). With the exception of two studies (Chalmers & Thomson, 1996; Dagan & Goldblatt, 2009), none of the studies provided a rationale for the interview questions asked, appearing to be guided by topics of interest. All but two studies (Hoskins et al., 2012; Robertson, 2000) provided the general themes of the interviews allowing some context from which to assess the findings. However only one study (Werner-Lin, 2007) provided example questions, preventing assessment of the potential impact of framing effect (Hawkes & Rowe, 2008). In addition, across the studies there was minimal discussion regarding the impact of the researcher on the study, including in formation of the research question and the impact on data collection. This becomes relevant when considering the extent to which women regarded the researcher as separate to their health provider and whether they felt required to justify access to services, possibly through the use of highly emotive language. It is possible that failure to reflect on, or at least discuss the role of the researcher reflects an expectation that identification of a method is adequate for the reader to understand the position that the researcher has taken; this is not the case (Chamberlain, 2000).

How do women at increased risk of breast cancer perceive risk?

Dimensional Views of Risk

Several studies reported that some women discussed dimensional or scalar risk estimates such as likelihood or severity. All women attending a high-risk clinic (Robertson, 2000) knew population risk figures and many reported attempting to create their own personal risk estimate, some in the form of a dimensional (numeric) estimate. Further, Beesley et al. (2013) found that out of a sample of 60 breast cancer survivors, five reported dimensional risk estimates.

The capacity to report numeric values does not mean that women endow the same estimates with the same meaning. Even when women are able to provide a numerical risk estimate, they can interpret the same estimate differently, and these interpretations appear to be used in decision-making. Keogh et al. (2011) uses the example that ‘one in three’ odds can mean two distinctly different things; with one interpretation being that she is not the ‘one’, whilst another understanding this to mean she will definitely die of breast cancer.

Categorical Perceptions of Risk

More women employed non-dimensional conceptualisations of risk. These are described either as probability-based categories such as ‘certainty’ (of getting cancer), or being ‘at risk’ (Chalmers & Thomson, 1996; Robertson, 2000), or in terms of membership of subjective categories such as ‘vulnerable’ (Beesley et al., 2013; Raveis & Pretter, 2005). This finding appears to be consistent across a range of sample types and data analysis methods, and women were often explicit about using these subjective categories. A common finding across studies was that women described their breast cancer risk as being ‘certain’. This finding appears well supported, with evidence being found in some women whose mothers had been

diagnosed with breast cancer (Kelly, 1980) and in some women who had first or second degree relatives with cancer (Chalmers & Thomson, 1996; Keogh et al., 2011). Werner-Lin (2007) also describes that, following BRCA testing, women felt that they were on a 'path towards cancer' and that without action they would experience the disease.

Worry

To different degrees, the role for emotion in relation to breast cancer risk was highlighted across all the included studies. This was usually characterised by descriptions of 'worry', which was described in both cognitive and emotional terms as aversive, ever-present, overwhelming and resistant to reassurance or counterargument. Emotion was less commonly described in terms of emotional states such as 'distress' or 'fear' although these were used either interchangeably with worry, or to describe the outcome of a process of worry.

Worry was characterised by a constant awareness. Women described the threat of breast cancer as a 'constant companion' (Dagan & Goldblatt, 2009; Robertson, 2000) and feeling chronically threatened by it (Kelly, 1980). Worry was also resistant to reassurance by explanation of the level of objective risk or by routine examinations or investigations (Beesley et al., 2013).

Emotion, though, may be argued to be a consequence rather than a component of risk perception. Evidence against this view comes from several studies that describe emotion in terms that suggest it is an independent component of the risk perception process. Several studies (Altschuler & Somkin, 2005; Keogh et al., 2011) indicate that although women knew 'intellectually' they were at increased risk, this information did not cause them to worry; possibly suggesting that 'intellectual knowledge of risk' and worry are related but distinct entities in their minds. Beesley et al. (2013) make a similar point, suggesting that worry

exists where women do not claim to consider dimensional or categorical representations of risk.

The ‘Lens’ of Family Experience

The studies showed that family experience of breast cancer framed and influenced the experience of risk. Several studies show that family experiences established a template that women used to consider risk, creating and organising expectations regarding their own futures. These templates were shaped by the family’s experiences of breast cancer, not simply by the presence or absence of a family history of the disease. The age of the first family member diagnosed with the disease was highlighted as relevant for many women’s perception of risk. Dagan and Goldblatt (2009) referred to this as the ‘family clock’ and Werner-Lin (2007) discusses a ‘danger zone’. Remaining healthy at the age at which their mother developed the disease provided a source of hope for future health (Dagan & Goldblatt, 2009) and was regarded as a benchmark that lessened women’s anxiety about developing the disease (Altschuler & Somkin, 2005).

Breast cancer in the family also acts as a model of how to respond to breast cancer risk. Hoskins et al. (2012) suggests that the young BRCA carriers understood risk through the ‘lens’ of family history through which they weighed ages, sites, and stages at which relatives were diagnosed when considering whether they might be at risk themselves. The results suggest that mothers’ coping (Dagan & Goldblatt, 2009; Kelly, 1980), the outcome of the disease (Dagan & Goldblatt, 2009; Kenen et al., 2003) and time since their relative’s diagnosis (Kenen et al., 2003) can shape a woman’s understanding of the disease and its saliency. Further, that the age and developmental stage of the woman when their relative developed breast cancer (Chalmers & Thomson, 1996; Dagan & Goldblatt, 2009) and the nature of their relationship and the role they played in caring for their sick relative also

influences women's risk perceptions (Dagan & Goldblatt, 2009; Kenen et al., 2003).

Additionally, women's identification with their family member with breast cancer (Bennett et al., 2010; Chalmers & Thomson, 1996; Raveis & Pretter, 2005), and perceived similarity to that family member (Kelly, 1980; Werner-Lin, 2007), can also shape risk perception.

Several studies suggest that family history can create a shift in the way women perceive themselves, for example by destroyed beliefs of immunity (Raveis & Pretter, 2005) and increasing awareness of her own vulnerability (Kelly, 1980; Raveis & Pretter, 2005).

Chalmers and Thomson (1996) see the family experience as providing a view of risk that women could move away from through a process of deliberation. The authors describe this process of individuation away from their family experience towards their own ideas concerning risk through three phases. The first being the process of 'living' the breast cancer experience through their relative with the disease. The second stage involves the development of a risk perception. The third being a process of 'putting risk in its place' and integrating risk into a view of oneself.

What Role do Risk Perceptions Play in Decisions Regarding Risk-Reducing Strategies?

Emotion is a Proximal Determinant of Decision Outcome

Women were often explicit in describing their decision-making goals in terms of managing worry, anxiety or vulnerability, rather than cancer risk (Beesley et al., 2013; Robertson, 2000). Robertson (2000) found that women managed their anxiety about being 'at-risk' for breast cancer by managing their bodies and adhering to a low-risk lifestyle. Beesley et al. (2013) concludes that vulnerability motivates women to seek CRRM and goes further to suggest that this appeared to be more relevant than objective risk understanding in the decision-making process. Others cited worry, fear or anxiety as proximal determinants of

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

decision-making across a range of risk-reducing options (Altschuler & Somkin, 2005; Bennett et al., 2010; Dagan & Goldblatt, 2009; Kelly, 1980; Kenen et al., 2003; Keogh et al., 2011; Sheinfeld Gorin & Albert, 2003).

Altschuler & Somkin (2005) reported higher rates of anxiety in women who opted for chemoprevention compared to those who refused, and Bennett et al. (2010) found that women who had high levels of breast cancer worry emphasised the need for mammographic screening and had a lower reliance on breast self-examination when compared to those who had lower breast cancer worry. Sheinfeld Gorin and Albert (2003) propose that worry is a key discriminator between ‘risk acceptors’ and ‘normalizers’ and suggest that these groups act on risk in different ways, with acceptors making lifestyle choices to take advantage of their perceived shortened lifespan.

Existence of Risk Factors

Several studies suggest that women become motivated to take precautions when they learn of a risk factor that applies to them personally. This appears to reflect the existence of the risk factor and its personal relevance, rather than any sense of either level of risk attributable to that factor or aggregate risk. Kelly (1980) suggests that women felt a need to learn as much as they can about risk reduction because they do not wish to unknowingly miss opportunities to reduce risk. A number of studies underline women’s attempts to engage in healthier lifestyles as a method of reducing their risk. In one of the groups conceptualised by Keogh et al. (2011), there was an attitude of being ‘concerned about cancer risk, so do something’, characterised by a belief that action could reduce risk and resulting in women opting for a healthy lifestyle, reducing stress and monitoring their bodies. Additionally, Kenen et al. (2003) highlighted that many women believed that eating a healthy diet, reducing stress or having the ‘right attitude’ might help ward off cancer, or was at least worth doing. Further,

Robertson (2000) suggests that women develop an 'at-risk' consciousness which results in women, to different degrees, engaging in health practices as 'self-care' strategies for managing their perceived risk and when they don't, they exhort themselves to do so.

Discussion

Summary

This qualitative synthesis was designed to establish the terms in which women at increased risk of breast cancer described this risk and how their mental representations of risk influenced choices of risk-reducing interventions. Women perceived risk in several ways, with some evidence that women represent risk in a dimensional way, and more evidence for categorical representations of risk. Women often described states of worry or emotional states such as fear; characterised by constant awareness, a chronic state of threat and negative emotion. Some women reported this worry as being independent to their knowledge of their risk status and resistant to reassurance. A further way of perceiving risk appeared to be experiential, where women directly inferred risk from their family experiences and some evidence that through active deliberation women could individualise this risk (Chalmers & Thomson, 1996). Women stated that they made risk reduction choices to reduce aversive states such as worry or because they saw specific risk factors that could be reduced through behavioural change. The degree to which this behaviour could reduce risk seemed irrelevant to women's uptake of risk-reducing behaviour.

Empirical and Theoretical Relevance

Utility theories conceptualise risk in terms of dimensional estimates of outcome likelihood and severity, and decision-making in terms of the extent to which choices can reduce these risks (Hochbaum, 1958; Rogers, 1975, 1983). These theories appear to be of limited use in women at increased risk of breast cancer as only a few women were found to use dimensional likelihood estimates. This begs the question of why empirical tests often support these models, albeit often

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

with small effect sizes (van Dijk et al., 2003; Katapodi et al., 2004). It is surmised that, either participants in quantitative studies construct a dimensional estimate from existing representations for the specific purpose of answering the question, or that they held a dimensional estimate at some point but that these were not prominent in the decision process.

Women's use of subjectively defined categories fits with the findings of Lippman-Hand and Fraser (1979) who suggest that people interpret risk in a binary form, Margolis (1996) who suggests that people view risk as either significant, or negligible, and Cameron, Sherman, Marteau and Brown's (2009) concept of 'chunking'. This finding also appears consistent with Loewenstein et al.'s (2001) suggestion that uncertain situations often promote responses which have binary characteristics and that neglect elements of probability. Women's categorisation of risk means that their thinking about risk will be influenced by the meanings that they attach to category labels such as 'low', 'moderate' or 'high'. These labels will be idiographic, with potential variance in meaning between individuals (Brown, Nowlan, Taylor, & Morley, 2013). Thus, understanding categorical risk perception will entail determining what women mean by the categories that they use. It is also significant that categorical risk perceptions were generally not mentioned by women as being responsible for their decision-making. Thus, these categories may either not be relevant considerations, or possibly, are not proximal to the decision outcome.

In the majority of studies, women discussed risk with reference to fear, worry and anxiety. It is possible that women were worried and fearful because they were at increased risk; that emotion was the result of an increased risk perception or increased risk status (Sivell et al., 2008). However, the reported discrepancy between emotional and intellectual understandings of risk, suggest that these may be distinct ways of perceiving risk. This suggestion seems further supported by the finding that emotion was resistant to reassurance by explanation about level of risk.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

The finding that worry seems to play a role in how risk is perceived and acted on appears largely compatible with more recent theoretical developments, which suggest that people process information using two modes: experiential and deliberative (dual process models, Leventhal et al., 2003; Loewenstein et al., 2001). The deliberative system emphasises cognitive representations and the experiential system is affective, intuitive and automatic (Slovic & Peters, 2006), which appears to fit with women's descriptions.

However, dual process theories suggest a stronger role for dimensional or categorical estimates of risk in decision-making than found in this review. We suggest two reasons why emotive representations, such as worry, may dominate. First, breast cancer is an inherently emotive topic, particularly amongst women who have personal or vicarious experience of it. Second, dual process models suggest that emotive modes will dominate when people lack resources to engage in deliberative thought (Loewenstein et al., 2001), as may happen when women experience negative emotions or feel challenged by the complexity of decisions that they are faced with.

Women appeared to understand and respond to risk using a script defined by experience with breast cancer. For many, this was a family script, the narratives of which, rather than simply the presence of cancer in the family, influenced how risk was understood. It is possible that family experience plays a greater role in the perception of risk at the initial stages of formation of an individual risk perception (Chalmers & Thomson, 1996). The importance of family history in shaping risk perceptions is also highlighted in a sample at increased genetic risk of disease (Sivell et al., 2008) and fits with the suggestion that people use their personal experience as a standard by which to assess risk (Grenning, Dollinger, & Pitz, 1996), conceivably through the construction of mental scenarios (Gregory, Cialdini, & Carpenter, 1982). The findings also appear to be in line with the concept of 'experiential knowledge' (a process that emerges and is shaped by the identity, circumstances, experiences and interests

of the knower) that impacts upon women's perceptions of their cancer risk (D'Agincourt-Canning, 2005).

The review focuses on women's perceptions of risk and the aspects of risk perception that women feel are relevant to their uptake of risk-reducing options. It is of note however, that risk perception makes up only one of a range of factors suggested by the empirical literature to be relevant to this decision-making process. A systematic review of the quantitative and qualitative data in this area (Howard et al., 2009) splits these relevant factors into three categories. Firstly, physical and medical factors such as BRCA status, previous breast cancer history, age, parity and menopausal status are evidenced to influence decision-making in this area. However, the review highlights that at times this evidence is mixed and somewhat contradictory. Secondly and somewhat in line with the findings of this review, there is evidence that psychological factors including cancer worry and risk perception play a role in the uptake of a range of risk-reducing options. Finally, Howard et al. (2009) highlight that social context, including patterns and personal experience of cancer in the family, alongside family obligations such as holding a caring role within the family, can in some cases, impact upon this decision-making process.

More broadly than the social factors identified within the Howard et al. (2009) review, international variation in uptake of risk reducing options (Metcalf et al., 2008) may suggest a cultural difference in the acceptability of risk-reducing options, both for women and health care professionals (Julian-Reynier et al., 2001). Variation in the availability of different risk-reducing options may also play a role in women's decision-making process (Metcalf et al., 2008).

Strengths and Limitations of the Review

The review offers a unique synthesis of qualitative data regarding risk perception and decision-making in a sample of women at increased risk of breast cancer. The review aims to address this gap in understanding in a rigorous way, using systematic search methods and drawing on guidelines (Popay et al., 2006) to increase the transparency of the narrative synthesis process. Additionally, the use of the CASP (CASP, 2013) tool, has allowed the quality of studies to be assessed in a consistent and replicable way.

Qualitative data were selected for synthesis as it allows new insights into risk perception theory and the data synthesised appears to offer findings of empirical and theoretical value. However, we are mindful that important phenomena are often implicit, otherwise concealed from participants' insights or deliberately or inadvertently withheld (Knox & Burkard, 2009). The synthesis therefore provides a useful, but partial understanding, which needs to be considered in light of the available quantitative literature; particularly research that highlights the range of factors that potentially influence decision-making in this area (Howard et al., 2009).

As few studies specifically aimed to examine risk perception, the review is restricted because data in many studies were collected to examine different research questions. In particular, it is unwise to make conclusions about the absence of phenomena because studies may not have been specifically designed to capture them. With the exception of Kenen et al. (2003), there is limited interpretation of data within the framework of health decision theory. Whilst participants in these studies have spontaneously provided suitable material for this review, theory development may be aided by investigations that involve decision-making theories.

Practical Implications and Future Research

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

The findings of the review alongside recognition that people experience difficulty in understanding and using likelihood information (Lipkus, Samsa, & Rimer, 2001) and may not even attempt it (Schneider, 2001), indicate that we should not expect women to have a detailed dimensional estimate of risk and to understand the proportions by which each risk-reducing option will reduce risk.

The extent to which women should be encouraged to form this understanding and use deliberative processing styles is a contentious one. Decision aids used to improve the quality of decision-making in this sample are usually based on the premise of traditional utility models, with the expectation that women are willing and able to deliberately weigh up their decision. However, some researchers have suggested that reliance on affect is necessary to form good decisions (Slovic & Peters, 2006) and others have highlighted the potential harm that can be caused by encouraging the use of deliberative processing styles (De Vries, Fagerlin, Witteman, & Scherer, 2013). Of course, the conceptualisation of a 'good' decision alluded to in the above work is derived from experimental studies where 'good' decisions are defined by the methodology used. In real-life medical decisions, determining whether decisions are 'good' is more difficult and likely to be defined by process rather than outcome (Elwyn & Myron-Schatz, 2009). Thus, the question of whether heuristically-led decision-making leads to 'good' decisions, and how these processes can be improved, in practice requires the identification of criteria for decision-making that accept that patients will make decisions heuristically (Elwyn & Myron-Schatz, 2009).

Thus, further research, particularly qualitative studies that set out specifically with the aim of understanding the concept of risk perception, would be helpful alongside greater discussion of the relative weighting of different aspects of risk perception in decision-making. Greater research is also needed in the value of processing information and decision-making using deliberative and affective styles.

References

- Altschuler, A., & Somkin, C. P. (2005). Women's decision making about whether or not to use breast cancer chemoprevention. *Women & Health, 41*, 81-95.
doi:10.1300/J013v41n02_06
- Amir, M., & Ramati, A. (2002). Post-traumatic symptoms, emotional distress and quality of life in long-term survivors of breast cancer: A preliminary research. *Journal of Anxiety Disorders, 16*, 191-206. doi:10.1016/S0887-6185(02)00095-6
- Aro, A. R., Pilvikki Absetz, S., van Elderen, T. M., van der Ploeg, E., & van der Kamp, L. J. (2000). False-positive findings in mammography screening induces short-term distress-breast cancer-specific concern prevails longer. *European Journal of Cancer, 36*, 1089-1097. doi: 10.1016/S0959-8049(00)00065-4
- Bao, T., Prowell, T., & Stearns, V. (2006). Chemoprevention of Breast cancer: Tamoxifen, raloxifene, and beyond. *American Journal of Therapeutics, 13*, 337-348.
doi:10.1097/00045391-200607000-00011
- Beesley, H., Holcombe, C., Brown, S. L., & Salmon, P. (2013). Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: Analysis of 60 consecutive cases in a specialist breast unit. *Breast, 22*, 179-184.
doi:10.1016/j.breast.2012.06.005.
- Bennett, P., Parsons, E., Brain, K., & Hood, K. (2010). Long-term cohort study of women at intermediate risk of familial breast cancer: Experiences of living at risk. *Psycho-Oncology, 19*, 390-398. doi:10.1002/pon.1588
- Bower, J.E., Ganz, P.A., Desmond, K.A. Rowland, J.H., Meyerowitz, B.E., & Belin, T.R.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- (2000). Fatigue in breast cancer survivors: Occurrence, correlates and impact on quality of life. *Journal of Clinical Oncology*, 18, 743–753
- Bradbury, A. R., & Olopade, O. I. (2007). Genetic susceptibility to breast cancer. *Reviews in Endocrine and Metabolic Disorders*, 8, 255-267. doi:10.1007/s11154-007-9038-0
- Bradley, C. J., Bednarek, H. L., & Neumark, D. (2002). Breast cancer survival, work, and earnings. *Journal of Health Economics*, 21, 757-779. doi: 10.1016/S0167-6296(02)00059-0
- Brown, S. L., Nowlan, L., Taylor, P. J., & Morley, A. M. (2013). Fuzzy risk perception: Correlates of “fuzzy” and specific measures of outcome likelihood in young drinkers. *Journal of Experimental Psychology: Applied*, 19, 120-129. doi: 10.1037/a0033284
- Cameron, L. D., Sherman, K. A., Marteau, T. M., & Brown, P. M. (2009). Impact of genetic risk information and type of disease on perceived risk, anticipated affect, and expected consequences of genetic tests. *Health Psychology*, 28, 307. doi: 10.1037/a0013947
- Cancer Research UK. (2013). *Breast Cancer Key Facts*. Retrieved from: <http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/breast-cancer/cancerstats-key-facts-on-breast-cancer>.
- Chalmers, K., & Thomson, K. (1996). Coming to terms with the risk of breast cancer: Perceptions of women with primary relatives with breast cancer. *Qualitative Health Research*, 6, 256-282. doi: 10.1177/104973239600600207
- Chamberlain, K. (2000). Methodolatry and qualitative health research. *Journal of Health Psychology*, 5, 285-296. doi: 10.1177/135910530000500306
- Critical Appraisal Skills Programme. (2013). Critical Skills Appraisal Program: Qualitative Research Checklist 31.05.13. Retrieved from www.casp-uk.net
- Dagan, E., & Goldblatt, H. (2009). The twilight zone between health and sickness: A

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- qualitative exploration with asymptomatic BRCA1 and 2 mutation carriers. *Women & Health*, 49, 263-279. doi:10.1080/03630240903158321
- D'Agincourt-Canning, L. (2005). The effect of experiential knowledge on construction of risk perception in hereditary breast/ovarian cancer. *Journal of Genetic Counseling*, 14, 55-69. doi:10.1007/S10897-005-1500-0
- De Vries, M., Fagerlin, A., Witteman, H. O., & Scherer, L. D. (2013). Combining deliberation and intuition in patient decision support. *Patient education and counseling*, 91, 154-160. doi: 10.1016/j.pec.2012.11.016
- Domchek, S. M., & Rebbeck, T. R. (2007). Prophylactic oophorectomy in women at increased cancer risk. *Current Opinion in Obstetrics and Gynecology*, 19, 27-30. doi: 10.1097/GCO.0b013e32801195da
- Easton, D. F., Bishop, D. T., Ford, D., & Crockford, G. P. (1993). Genetic linkage analysis in familial breast and ovarian cancer: results from 214 families. The breast cancer linkage consortium. *American Journal of Human Genetics*, 52, 678-701.
- Elwyn, G., Miron-Schatz, T. (2009). Deliberation before determination: The definition of good decision-making. *Health Expectations*, 13, 139-147. doi: 10.1111/j.1369-7625.2009.00572.x
- Ferrero, J.M., & Namer, M. (1994). Pathologie mammaire. *Archives D'anatomie et de Cytologie Pathologiques*, 42, 198-205.
- Greening, L., Dollinger, S. J., & Pitz, G. (1996). Adolescents' perceived risk and personal experience with natural disasters: An evaluation of cognitive heuristics. *Acta Psychologica*, 91, 27-38. doi: 10.1016/0001-6918(94)00040-9

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- Gregory, W. L., Cialdini, R. B., & Carpenter, K. M. (1982). Self-relevant scenarios as mediators of likelihood estimates and compliance: Does imagining make it so?. *Journal of Personality and Social Psychology*, 43, 89.
- Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A., & Watson, M. (2004). Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer. *Social Science & Medicine*, 59(3), 553-565. doi:10.1016/j.socscimed.2003.11.025
- Hawkes, G., & Rowe, G. (2008). A characterisation of the methodology of qualitative research on the nature of perceived risk: trends and omissions. *Journal of Risk Research*, 11, 617-643. doi:10.1080/13669870701875776
- Hochbaum, G.M. (1958). *Public participation in medical screening programmes: A socio-psychological study* (Public Health Service Publication 572), Washington, DC: Government Printing Office.
- Hopwood, P., Lee, A., Shenton, A., Baildam, A., Brain, A., Lalloo, F., ... & Howell, A. (2000). Clinical follow-up after bilateral risk reducing ('prophylactic') mastectomy: mental health and body image outcomes. *Psycho-Oncology*, 9, 462-472. doi: 10.1002/1099-1611(200011/12)9:6<462::AID-PON485>3.0.CO;2-J
- Hoskins, L. M., Roy, K. M., & Greene, M. H. (2012). Toward a new understanding of risk perception among young female BRCA1/2 "previvors". *Families Systems & Health*, 30, 32-46. doi:10.1037/a0027276
- Howard, A. F., Balneaves, L. G., & Bottorff, J. L. (2009). Women's decision making about risk-reducing strategies in the context of hereditary breast and ovarian cancer: a systematic review. *Journal of genetic counseling*, 18, 578-597.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Julian- Reynier, C. M., Bouchard, L. J., Evans, D. G., Eisinger, F. A., Foulkes, W. D., Kerr, B., ... & Sobol, H. H. (2001). Women's attitudes toward preventive strategies for hereditary breast or ovarian carcinoma differ from one country to another. *Cancer*, 92, 959-968. doi: 10.1002/1097-0142

Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Preventive Medicine*, 38, 388-402.
doi:10.1016/j.ypmed.2003.11.012

Kelly, P. T. (1980). Counselling needs of women with a maternal history of breast cancer. *Patient Counselling & Health Education*, 2(3), 118-124.

Kenen, R., Ardern-Jones, A., & Eeles, R. (2003). Living with chronic risk: Healthy women with a family history of breast/ovarian cancer. *Health, Risk and Society*, 5, 315-331.
doi: 10.1080/13698570310001607003

Keogh, L. A., McClaren, B. J., Apicella, C., & Hopper, J. L. (2011). How do women at increased, but unexplained, familial risk of breast cancer perceive and manage their risk? A qualitative interview study. *Hereditary Cancer in Clinical Practice*, 9, 1-11.
doi:10.1186/1897-4287-9-7

Knox, S., & Burkard, A. W. (2009). Qualitative research interviews. *Psychotherapy Research*, 19, 566-575. doi: 10.1080/10503300802702105

Leventhal, H., Brissette, I., & Leventhal, E. (2003). The common sense model of self-regulation of health behaviour. In: L.D. Cameron & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 42-65). New York: Routledge.

Lipkus, I. M., Samsa, G., & Rimer, B. K. (2001). General performance on a numeracy scale among highly educated samples. *Medical Decision Making*, 21, 37–44.

doi:10.1177/0272989X0102100105

Lippman-Hand, A., & Fraser, F. C. (1979). Genetic counseling: provision and reception of information. *American Journal of Medical Genetics*, 3, 113-127.

Loewenstein, G.F., Weber, E.U., Hsee, C.K., & Welch, E.S. (2001). Risk as feelings.

Psychological Bulletin, 127, 267–286. doi:10.1037//0033-2909.127.2.267

Margolis, H. (1996). *Dealing with risk: Why the public and the experts disagree on environmental issues*. Chicago: University of Chicago Press.

McPherson, K., Steel, C., & Dixon, J. M. (2000). ABC of breast diseases: Breast cancer epidemiology, risk factors, and genetics. *British Medical Journal*, 321, 624-628.

doi:10.1136/bmj.321.7261.624

Meiser, B., Butow, P., Friedlander, M., Schnieden, V., Gattas, M., Kirk, J., ... & Tucker, K. (2000). Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. *Journal of Clinical Oncology*, 18, 2250-2257.

Metcalfe, K. A., Birenbaum- Carmeli, D., Lubinski, J., Gronwald, J., Lynch, H., Moller, P., ... & Narod, S. A. (2008). International variation in rates of uptake of preventive options in BRCA1 and BRCA2 mutation carriers. *International journal of cancer*, 122, 2017-2022. doi: 10002/ijc.23340

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. (2009). Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement. *PLoS Med* 6(6):

e1000097. doi:10.1371/journal.pmed1000097

National Comprehensive Cancer Network. (2008). *NCCN clinical practice guidelines in oncology. Genetic/familial high-risk assessment: breast and ovarian*. Retrieved from http://www.nccn.org/professionals/physician_gls/PDF/genetics_screening.pdf.

National Institute of Clinical Excellence. (2013). *Familial breast cancer: Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer*. Retrieved from <http://www.nice.org.uk/guidance/index.jsp?action=byID&o=14188>

Nelson, H. D., Fu, R., Griffin, J. C., Nygren, P., Smith, M. B., & Humphrey, L. (2009). Systematic review: Comparative effectiveness of medications to reduce risk for primary breast cancer. *Annals of Internal Medicine*, 151, 703-715. doi:10.7326/0000605-200911170-00147

Office of National Statistics. (2012): *Breast cancer: Incidence, mortality and survival, 2010: Female breast cancer in England: Incidence and mortality*. Retrieved from http://www.ons.gov.uk/ons/dcp171780_280355.pdf

Payne, D.K., Biggs, C., Tran, K., Borgen, P. I., & Massie, M. J. (2000). Women's regrets after bilateral prophylactic mastectomy. *Annals of Surgical Oncology*, 7, 150-154.

Popay, J., Roberts, H., Sowden, A., Petticrew, M., Arai, L., Rodgers, M., ... & Duffy, S. (2006). Guidance on the conduct of narrative synthesis in systematic reviews. *A product from the ESRC Methods Programme. Version, 1*.

Raveis, V. H., & Pretter, S. (2005). Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psycho-Oncology*, 14, 49-60. doi: 10.1002/pon.819

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- Rebbeck, T. R., Friebe, T., Lynch, H. T., Neuhausen, S.L., van't Veer, L., Garber, J.E.,...Weber, B.L. (2004). Bilateral prophylactic mastectomy reduces breast cancer risk in *BRCA1* and *BRCA2* mutation carriers: The PROSE study group. *Journal of Clinical Oncology*, 22, 1055–1062. doi: 10.1200/JCO.2004.04.188
- Reyna, V. F., & Adam, M. B. (2003). Fuzzy–trace theory, risk communication, and product labeling in sexually transmitted diseases. *Risk Analysis*, 23, 325-342. doi:10.1111/1539-6924.00332
- Robertson, A. (2000). Embodying risk, embodying political rationality: Women's accounts of risks for breast cancer. *Health, Risk & Society*, 2, 219-235. doi:10.1080/713670161
- Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *Journal of Psychology*, 91, 93-114.
- Rogers, R.W. (1983). Cognitive and physiological processes in fear appeals and attitude change: A revised theory of protection motivation. In J. Cacioppo & R. Petty (Eds.), *Social Psychophysiology* (pp.153-177). New York: Guilford Press.
- Schneider, S. L. (2001). In search of realistic optimism. Meaning, knowledge, and warm fuzziness. *American Psychologist*, 56, 250–263
- Sestak, I., Cuzick, J., Evans, D.G, & Kwong, A. (2012). Prevention of breast cancer. In M.J. Dixon (Ed.), *ABC of Breast Diseases*. (pp. 47-50). Chicago: Wiley-Blackwell.
- Sheinfeld Gorin, S., & Albert, S. M. (2003). The meaning of risk to first degree relatives of women with breast cancer. *Women & Health*, 37, 97-117. doi:10.1300/J013v37n03_07
- Sivell, S., Elwyn, G., Edwards, A., Gaff, C., Clarke, A., Iredale, R., & ... Thornton, H. (2008). How risk is perceived, constructed and interpreted by clients in clinical genetics, and

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- the effects on decision-making: Systematic review. *Journal Of Genetic Counseling*, 17, 30-63. doi:10.1007/s10897-007-9132-1
- Skinner, C. S., Kreuter, M. W., Kobrin, S., & Strecher, V. J. (1998). Perceived and actual breast cancer risk optimistic and pessimistic biases. *Journal of Health Psychology*, 3, 181-193. doi: 10.1177/135910539800300203.
- Slovic, P., Finucane, M.L., Peters, E., & MacGregor, D.G. (2002). The affect heuristic. In T. Gilovich, D. Griffin. & D. Kahneman, (Eds.), *Heuristics and biases: The psychology of intuitive judgment* (pp. 397–420). New York: Cambridge University Press.
- Slovic, P., & Peters, E. (2006). Risk perception and affect. *Current directions in psychological science*, 15, 322-325. doi 10.1111/j.1467-8721.2006.00461.x
- Tuttle, T., Habermann, E., Abraham, A., Emory, T., & Virnig, B. (2007) Contralateral Prophylactic Mastectomy for Patients with Unilateral Breast Cancer. *Expert Review Anticancer Therapy*, 7,1117-1122.
- van Dijk, S., Otten, W., Zoetewij, M., Timmermans, D., van Asperen, C., Breuning, M., Tollenaar, R., Kievit, J. (2003). Genetic counselling and the intention to undergo prophylactic mastectomy: effects of a breast cancer risk assessment. *British Journal Of Cancer*, 88, 1675- 1681.
- Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, 39, 806-820. doi: 10.1037/0022-3514.39.5.806
- Weinstein, N.D. (1993). Testing four competing theories of health-protective behavior. *Health Psychology*, 12, 324–333.
- Weinstein, N. D., Kwitel, A., McCaul, K. D., Magnan, R. E., Gerrard, M., & Gibbons, F. X.

(2007). Risk perceptions: assessment and relationship to influenza vaccination. *Health Psychology*, 26, 146-151. doi:10.1037/0278-6133.26.2.146

Werner-Lin, A. V. (2007). Danger zones: Risk perceptions of young women from families with hereditary breast and ovarian cancer. *Family Process*, 46, 335-349.
doi:10.1080/00981380802173509

**How women at high risk of breast cancer perceive risk and make decisions concerning
risk when they choose risk-reducing mastectomy²**

Hannah. G. Fielden
University of Liverpool

² To be submitted to *Journal of Psychology and Health*: Word limit: 30 double-spaced manuscript pages.

Abstract

Risk-Reducing Mastectomy (RRM) is a surgical procedure aimed at reducing risk of breast cancer. RRM can have a range of side effects and questionable risk reduction benefits, making it a controversial option. Previous research using a case series design has indicated that women may be driven to access RRM by a sense of vulnerability and a wish for cosmesis. This study aimed to explore how women made decisions regarding RRM using a qualitative research design. Using a semi-structured interview, 12 women provided their experience of making decisions regarding RRM. Results suggest that women's decisions to undergo RRM was driven by fear of breast cancer and the belief that they should do all they can to reduce risk, not by a utility-based comparison of risks of cancer and side effects of RRM. Women reported engaging in deliberative decision-making strategies, but these were seen as justifications for a decision that had already been taken. These findings provoke the question of whether women's decisions should be accepted on the basis that negative affect reduction is a valid and viable goal in autonomous patient decision-making, or whether utilitarian decision-making ought to be encouraged.

Keywords: Risk-reducing mastectomy, decision-making, breast cancer, qualitative.

**How Women at High Risk of Breast Cancer Perceive Risk and Make Decisions
Concerning Risk When They Choose Risk-Reducing Mastectomy**

Currently, approximately one in eight women in the United Kingdom will develop breast cancer in their lifetime (Cancer Research UK [CRUK], 2013) and two in ten women diagnosed will not survive over five years (CRUK, 2013). For many, the diagnosis and treatment of the disease has a multitude of negative physical, psychological and psychosocial consequences that can continue long after treatment is complete (Amir & Ramati, 2002; Bower, et al., 2000; Bradley, Bednarek, & Neumark, 2002). Individuals' breast cancer risk can be estimated with some degree of confidence in women who both have and have not experienced the disease. This information can then be used to guide access to preventative options.

In the UK, women identified to be at 'high risk' of breast cancer can choose to opt for risk-reducing mastectomy (RRM), the surgical removal of healthy breast tissue to reduce risk (National Institute of Clinical Excellence [NICE], 2013). Contralateral RRM (CRRM) usually occurs in the opposite breast to which cancer has occurred. Bilateral RRM (BRRM) is mastectomy of both breasts; usually in women who do not have a personal history of the disease, but also when breast tissue remains from previous treatment. The magnitude of RRM's risk reduction capabilities increases as estimates of objective risk increase; in some cases reducing risk by up to 95% (Rebbeck et al., 2004). However, the precise survival benefits of the procedure remain unclear (Lostumbo, Carbine, Wallace, & Ezzo, 2004; Sestak, Cuzick, Evans, & Kwong, 2012).

RRM can have negative consequences, making it a controversial option (Drife, 1992; Stefanek, Hartmann, & Nelson, 2001). Pain (Payne, Biggs, Tran, Borgen, & Massie, 2000) and difficulties relating to appearance and femininity (Hopwood et al., 2000) have been

reported. Surgical complications and reoperations are also common (Gabriel et al., 1997).

Women, in 14% of cases were found to regret their decision to undertake CRRM (Frost et al., 2005) a figure that rises to 19% in relation to BRRM (Frost et al., 2000). Thus, when making decisions regarding RRM, consideration needs to be given to the risk of future breast cancer, the extent to which this risk can be reduced by RRM, and the risk of side effects and complications. Given the importance and magnitude of this decision, understanding women's decision-making process is vital.

Decision-Making Regarding RRM

Utilitarian risk decision-making models suggest that people make decisions about risk by estimating the likelihoods and values of differing outcomes then logically integrating these to achieve decisions (Hochbaum, 1958; Rogers, 1975, 1983; Weinstein, 1980, 1993). In research investigating RRM decision-making, evidence that higher dimensional risk perception is associated with greater uptake of the RRM in hypothetical and actual decision-making situations (Howard, Balneaves, & Botroff, 2009; Kataopdi, Lee, Facione & Dodd, 2004; van Dijk et al., 2003) appears to be consistent with utilitarian models. However, the role of dimensional risk perception in uptake of RRM has been questioned (Appleton, Fry, Rees, Rush, & Cull, 2000; Hoskins, Roy, & Greene, 2012), with a recent review concluding that the evidence for the effects of perceived risk on the use of services (including RRM) is weak (Sivell et al., 2008).

Cancer related distress, worry or anxiety has also been associated with higher uptake of RRM in quantitative (Howard et al., 2009; Meiser et al., 2000; Stefanek, Helzlsouer, Wilcox, & Houn, 1995; van Dijk et al., 2003) and qualitative (Hoskins et al., 2012; Howard et al., 2009) research. Evidence for the role of emotion in uptake of RRM appears to support dual-process theories of health decision-making, which proposes that people process and act on risk using

two distinct modes of thinking: deliberative and experiential (Peters, McCaul, Stefanek, & Nelson, 2006). Whilst the deliberative system is much like the systems proposed by utilitarian models, the experiential process is fast and intuitive (Peters et al., 2006).

Mixed and at times weak evidence to support current theory may be partly due to a predominance of quantitative literature in the area (Hawkes & Rowe, 2008). Lack of qualitative literature prevents understanding of the factors that women feel are important to their decision-making process and may have limited theoretical development. Additionally, as very few studies link their findings to health theory, the ability to draw conclusions that could lead to theory advancement is limited.

A recent qualitative study by Beesley, Holcombe, Brown, and Salmon (2013) appears to suggest a stronger position for the role of emotion in decision-making than in previous research. The study concludes that quantitative risk perception played little or no role in women's decision-making process; the decision to undertake CRRM was largely driven by an overriding sense of vulnerability and an awareness that risk existed. The study highlights that women explicitly stated that they did not consider risk in a dimensional way, nor did they consider the risks of side effects. These findings appear to contradict both utility and dual-process decision-making theories because this sense of vulnerability represents the dominant way in which women appraise risk. These findings create a tension between whether women's decisions should be accepted on the basis that negative affect reduction is an acceptable goal in autonomous patient decision-making, or whether efforts should be made to encourage more utilitarian decision-making. However the conclusions are limited by a case series design based on clinical notes, a sample limited to women obtaining CRRM and not BRRM, and lack of links to theory. It is important to examine whether these findings hold up

when data is directly provided by women considering both CRRM and BRRM and considered in the light of current risk perception theory.

Rationale and Aims

Understanding gained from current theory does not appear to adequately reflect how women actually make RRM decisions. In particular, the findings of Beesley et al. (2013) suggest that women use RRM as a means of reducing the negative affect associated with vulnerability to cancer, raising tension about the suitability of this approach to decision-making.

It is possible that a predominance of quantitative literature in the area may have stifled theoretical development that could more adequately explain Beesley et al.'s (2013) findings, and more broadly, decision-making in this area. In an effort to facilitate the development of new theoretical approaches, this study will provide a much-needed qualitative contribution to our understanding of how decisions to undergo RRM are made in a sample of women who have chosen to do so. By directly interviewing women rather than examining clinical records, the study will overcome the methodological limitations of the Beesley et al. (2013) study, allowing greater understanding of the decision-making process from the decision maker's perspective.

The study has two aims:

- To describe, using in-depth interviews, how women make decisions regarding RRM.
- To identify implications of the findings for the role of decision support for women facing RRM decisions and for psychological theory.

Method

Sample

A consecutive sample of twelve women was recruited from a large breast unit in North West England. All of the women approached regarding participation in the study agreed to take part, of which, all then went on to be interviewed.

Recruitment aimed to reflect the range of women who opted for RRM at the breast unit and therefore no limits were placed on type of surgery (CRRM or BRRM) or previous experience (personal history of breast cancer or not). This information was collected alongside age, family history of breast and other cancers, BRCA status, highest qualification achieved, and employment status. The 100% response rate provides confidence that the sample was sufficiently broad to represent the range of women who attended the unit. A condition of entry into the study was that women had to have made their decision to have RRM and have no plans to revisit the decisions in the subsequent three months. Women who had surgery were interviewed within three months of surgery.

Data Collection

The study was granted NHS ethical approval (13/NW/0421). Staff at the breast unit (breast care nurses, surgeons, psychologists) provided potential participants with information about the study. If women were interested and agreed to be contacted they were given an information sheet (appendix 5), which included all relevant ethical information (appendix 6 for additional detail regarding procedure and ethics).

A member of the research team contacted women by telephone one week after the information sheet was given. Additional information and reiteration that their participation was entirely voluntary was provided. If, at this point, women agreed to participate, a time was

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

arranged to meet, gain written consent (appendix 7) and complete the interview. Recruitment of participants was conducted in parallel with analysis, ending when the 12 interviews provided consistent findings.

Semi-structured, face-to-face interviews (20 to 70 minute duration) were conducted at private locations that were convenient to participants (home, work, or hospital). The trainee conducted 10 out of the 12 interviews; the Research Assistant who formed part of the research team conducted the remaining two. Semi-structured interviews offered the opportunity to explore questions relevant to the study whilst allowing participants the opportunity to answer freely. In order to characterise the sample, participants completed a brief demographic information sheet (appendix 8) and the Hospital Anxiety and Depression Scale ([HADS] Zigmond & Snaith, 1983, appendix 9). The HADS was selected due to its brevity whilst maintaining good validity (Bjelland, Dahl, Haug, & Neckelmann, 2002).

The interviews followed an interview guide (appendix 10), developed in response to the findings of Beesley et al. (2013) and previous literature in the area. Predetermined topics included: How women thought and felt before, during and after their decision-making regarding RRM and the role of risk perception in this process. Interviews were conversational using reflection and open-ended questions to allow participants to talk freely. Focused questions were used to gain more specific information and to address the tendency of interviewees to give socially appropriate or vague answers to generic questioning (Legard, Keegan, & Ward, 2003). Focused questions followed general questions to enable interviewees to respond freely to the former. Interviewers took a non-directive, non-judgmental stance to participants' responses. A protocol for dealing with distress (appendix 11) was available, but not required.

The interview guide was refined in response to the ongoing analysis in order to test and

develop the findings (see appendix 10 for refinements). Refinements included the addition of several questions asking women to provide a percentage estimate of their level of risk before and after RRM. These questions were added to explore whether women's descriptions of 'elimination' of risk reflected a misunderstanding of the risk-reducing capability of RRM, or whether women used such language in spite of recognition that the procedure could not eliminate risk. These questions were placed at the end of the interview to avoid influencing women's recall. Participants were given the option of receiving a summary of the results; eleven out of twelve chose to receive this information. Interviews were digitally recorded and then transcribed by an independent transcription company; the research team checked transcripts for accuracy. Field notes and reflections were kept by the interviewer to inform the analysis process. All data were stored in line with a data protection protocol (appendix 12).

Data Analysis

The study took a pragmatic approach to qualitative analysis that flexibly applies methods and epistemological positions as required by the data and the developing analysis (see appendix 6 for further details). This approach is similar to that advocated by Gwyn (2002) and enabled the researchers to overcome criticism that rigid adherence to specific method restricts the creative inquiry process (Barbour, 2001; Chamberlain, 2000; Salmon, 2003; Seale, 1999). By drawing on widely used and tested methodology the study was able to maintain creativity whilst retaining rigor. This approach to data analysis has previously been used by researchers addressing clinical communication data (e.g. Salmon, Mendick, & Young, 2011; Wright, Holcombe, & Salmon, 2004).

Each transcript was read and re-read individually by each member of the research team and then presented by the trainee and discussed together in a research meeting. Following each

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

research meeting the trainee used these discussions to form the ongoing analysis, which was then taken back to research meetings to be commented on and then discussed in light of new data. This was an ongoing process. A brief narrative of the key features of each interview was developed to aid remembering and reflection (appendix 13 for example).

Group analysis allowed consensus validity (Stiles, 1999). Periodic involvement from the wider research team was used to test the emerging analysis and increase credibility. Analysis paralleled data collection, informing the continued conceptual and procedural evolution of the interview guide (Seale, 1999; Stiles, 1993, 1999; Yardley, 2000) allowing testing and development of the emerging theory. Disagreements were encouraged and resolved through discussion. Dependability of the interpretation was increased by the development of an audit trail through meeting summaries (appendix 14, completed by the Research Assistant) and ongoing analysis records completed by the trainee (appendix 15 and 16).

The study followed a constant comparative approach within which the analysis moved between descriptive approaches and more interpretative approaches as required by the data. The analysis initially drew heavily on thematic analysis allowing identification of recurrent features of the participants' accounts (appendix 15). As the analysis progressed, and as required by the data, (e.g. when it was identified that that accounts may serve functions other than surface meanings), interpretive analysis and perspectives from sociolinguistic and discourse approaches were drawn upon. This allowed the data to be understood within the context of the whole interview and the wider analysis, and also within the context of the interview setting and wider social context. Pivotal cases, outliers and contradictions to the emerging analysis were highlighted and discussed. Conceptual categories (appendix 16) were developed as a result of this process and considered in relation to clinical and research utility, the catalytic validity and theoretical validity (Kincheloe & McLaren, 2000). Changes to the

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

conceptual categories during analysis were recorded throughout and tested through refinements to the interview guide.

Results

Sample Characteristics

Participants ranged in age from 25-65 years, (see table 1 for demographic information by participant). Three opted for BRRM and nine for CRRM. Four women had completed the surgery before the interview. The women had a diverse educational background, the highest being degree level and the lowest being National Vocational Qualification / GCSE. Four women had a known BRCA mutation and two were BRCA negative. BRCA status in the remaining sample was unknown at the time of the interview. One woman in the sample did not have a personal history of breast cancer, seven women had a family history of breast cancer and one participant had a family history of cancer other than breast cancer. One participant met the HADS cut off for elevated depression (>8) and eight for elevated anxiety (>8) (Snaith & Zigmond, 1994).

Table 1:

Demographic information

ID	Age range	Type of surgery	Highest qualification	Personal BC history	Time since Treat Cancer	Time since Diagnosis	Family BC history	Family cancer history (other than BC)	BRCA Status	HADS Depression total	HADS anxiety score
ID1	46-50	CRRM	Diploma	Y	12 months (m)	25 m	N	Y	Not taken	0	1
ID2	35-40	BRRM	GCSE	N	NA	NA	Y	N	Not possible	6	10
ID3	60-65	BRRM	O-levels	Y	14 m	20 m	Y	N	Positive	1	2
ID4	25-30	CRRM	NVQ	Y	6 m	12 m	N	N	Negative	5	8
ID5	46-50	CRRM	A-levels	Y	15 m	20 m	Y	N	Going for tests	4	8

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

ID6	46-50	CRRM	GCSE	Y	6 m	12 m	N	N	Positive	10	8
ID7	56-60	CRRM	NVQ	Y	5 m	12 m	Y	N	Positive	6	10
ID8	46-50	BRRM	GCSE	Y	25 m	34 m	Y	N	Positive	4	13
ID9	46-50	CRRM	Degree	Y	Unavail- able	24 m	N	N	Not taken	1	5
ID10	46-50	CRRM	GCSE	Y	24 m	84 m	N	N	Not taken	5	8
ID11	31-35	CRRM	A Level	Y	6 m	18 m	Y	N	Negative	2	7
ID12	46-50	CRRM	BSc	Y	1 m	7 m	Y	N	Not possible	3	11

Summary of Analysis

Overall, the findings suggested that women's decision to opt for RRM is primarily driven by fear that is characterised by a sense of menace involving beliefs relating to the implacability and undetectability of future cancer. Women held beliefs about the need to do everything possible to prevent cancer; these beliefs appear to translate the sense of menace into decision-making. Women then attempted to justify and rationalise the decision, but this seems to have little bearing on the decision outcome. Women's social environments, particularly discussion with their friends, family and peers and influence of the media, form an important context in which the second and third stages play out (see figure 1).

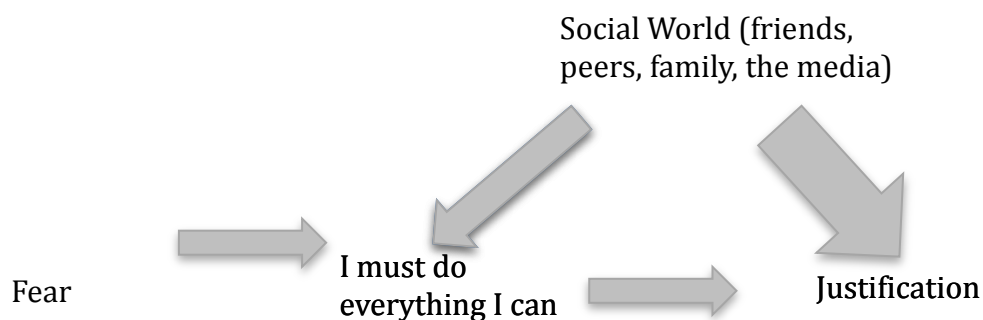


Figure 1. Diagrammatic representation of decision-making in RRM

Fear and Menace

Most women discussed their decision to opt for RRM in relation to fear of breast cancer: R:

“What do you think was driving that kneejerk (decision to have RRM), do you think?” P:

“Fear I think. I think it’s a fear factor that, you know...” (participant 9). Women talked about this fear being the main driver of their decision: *“Yeah. Just the fear of a comeback again is um is, is what... really that’s the main thing really, you know”* (participant 7). This fear was discussed together with a sense that breast cancer was a menace.

Menace was heightened by the perception that cancer could lurk undetected in the body:

“You know, your body can turn bandit at any point, can’t it?” (participant 1). Several women believed that screening and early detection technology was incapable of detecting the cancers that they were likely to experience. *“Yeah, just not being able to ever detect it, that is my main worry, that they could literally monitor the other one now for the rest of my life and still not find it. Because it has happened, it’s actually... If something that horrible has happened to you, you sort of don’t trust the tests anymore.”* (participant 5). Women also described being unaware of having the disease, often using highly emotive language and metaphor to describe their beliefs about the threat of cancer: *“You wouldn’t have felt the cancer that you had. So, that’s when the brain started ticking thinking so I might have it and not even know then, again. So it’s tormented me for quite a bit”* (participant 10). It is however possible to see how women’s positioning of the role of fear in their decision-making process may have been augmented by their current affect, in particular high levels of anxiety as suggested by the scores on the HADS (Zigmond & Snaith, 1983).

Some women described the likelihood of breast cancer occurrence as a certainty, again using emotive language in their description of the threat of breast cancer: *“I just think it’s going to come back anyway... I feel like I am just sitting like a little ticking time bomb”* (participant 8).

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

“It’s that I’m going from this really, almost certain breast cancer to actually [participant name], you, you have no reason not to become 53” (participant 12). For these women, the decision to opt for RRM appeared to be regarded as a decision between RRM and breast cancer.

Participant 2 was the only contributor who did not have a personal history of breast cancer and it seems likely that this influenced the themes elicited. In particular it was noted that for her, there was less discussion of fear in relation to breast cancer and it is possible that the role of fear in this decision-making process is more central to women who have a personal history of breast cancer. Instead, participant two talked about considering the impact that breast cancer could have on her children, relating it to her experience of having a mother who had the disease. She also described her decision to opt for RRM to be driven by a sense of the unknown in relation to whether she had the BRCA gene. Nonetheless, she did allude to her decision to opt for RRM as a decision between surgery or breast cancer: *“Mum kind of went oh, so, oh so you’re actually gonna do it?... Um and, and I just turned to Mum and I said, “Well, Mum, what’s the alternative? Go through what you’ve been through, which quite frankly looked pretty shit to me.” (participant 2).*

Often women described feeling that numerical risk was irrelevant to their decision. Some women highlighted the uniqueness of their case as to why statistics didn't apply: *“You know, if I’m looking at statistics, the majority of the women are aged 50 or over, and I’m 31. You know, those statistics don’t really relate to me as much as they do to other women...”* (participant 11). Others appeared to simply reject this risk information as irrelevant: R: *“if she’d have given you a lower number do you think that would have changed your mind?”* P: *“No, 'cause I think I’d made my mind up straightaway”* (participant 8). Several women described a sense that if risk was present, at any level, then it needed to be acted upon: *“Well if there was 1% chance that was enough for me”* (participant 10). *“Even if they’d said it was*

a 1% risk I probably still would have done it” (participant 11). Five women referred to their decision using the phrase ‘no brainer’ seemingly reflecting the lack of cognitive processing that they deemed was necessary to make the decision.

‘I must do everything I can’

When reflecting upon their decision to opt for RRM, almost all women referred to a need to do all in their power to prevent breast cancer. They saw electing to undergo RRM as a consequence of that. Some women expressed anticipatory guilt if breast cancer occurred and they felt they had not done everything they could to prevent it: “... *if it does come back and I didn’t do something about it when I could have done? And it was that, thinking I need to do it.*” (participant 10).

Perception of having done ‘all in their power’ allowed women to develop a sense of fatalism about developing breast cancer. This sense of fatalism appeared to be emotionally helpful, reducing fear and reducing the possibility of regret: “*God forbid, if it does come back, well that’s something I’ve got to do... deal with then, when it happens, if it happens. So um... but it’s still... I, I’d still know in my heart of hearts that I’d done everything I can do, you know*” (participant 7).

The centrality of this belief in the decision process is emphasised. Women described it as the cause of them choosing RRM. Unlike the justifications (described in the next section), when many women reported that considerations would not have made them change their minds, women were clear that this belief was a proximal factor in their decision.

All but two of the women with a personal history of the disease highlighted that they had requested RRM at the point of treatment for breast cancer. Women discussed their decision as immediate and often framed as ‘get them off’, referring to a woman’s breasts as external and

expendable. A number of women referred to their breasts as functional objects that they are no longer required: *“I’ve had my use of them for 50 odd years; I don’t need them no more now. I’ve had my children, so I can get on with it”* (participant 3). As highlighted within the quote, this theme is likely to be influenced by a woman’s age and life stage, particularly if she has, or intends to have, children. Elicitation of this theme may reflect the characteristics of the sample included.

Within the descriptions of needing to do ‘all in their power’, there appears to be a role for the social world; namely women’s peers and the media in shaping their decision-making process. Women discussed how their peers increased their awareness of the procedure: *“...a lady got talking to me in Asda... She said I’ve just been to see my consultant actually to get the other one removed. And I was standing there thinking, do you know that’s what I need to do...”* (participant 1). Several women referred to the media in increasing awareness and acceptability: *“I don’t know if I’d read something years ago um.. I know it seems to be more... people seem to be doing it more nowadays, you know”* (participant 7). Through increasing availability of information about risk-reducing options and determination of what was an acceptable measure to take in order to reduce risk, this social world appeared to shape what women perceived to be *all* they could do.

Justification

Women often described a decision-making process, discussing a range of reasons why they chose to opt for RRM. However this was often in the context of having identified that the decision was made quickly, often requested at the point of treatment for breast cancer and primarily driven by fear. Discussion of decision-making as a deliberative process within the interview appeared to reflect justification of their decision. This process of justification appeared to be emotionally helpful for some women.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Participant 9 illustrates this point when discussing her decision to opt for CRRM as a ‘kneejerk’ driven by fear, and identifying that she had requested RRM at the time of treatment for breast cancer. At this point she was told that although RRM was an option but that treatment for breast cancer needed to be completed first. She describes that during this time she considered additional aspects of her decision: “...*during that period, that’s when the practical considerations came into it, that actually there’s some practical benefits to this as well as psychological benefits.*” However, that these practical considerations played no role in her decision-making: R: “*Do you think if there’d have been sort of negatives practical considerations that would have swayed your decision in any way?*” P “...*No, I don’t think, I don’t think if practically it had been more difficult, I think I probably would still have gone ahead with it.*” She goes on to describe this period as emotionally helpful: “*it was an unusual... way to make a decision for me, but it was the emotion made the decision, the moving it to the practical ... just, I think, helped me rationalise it... and helped me make myself feel comfortable with an emotional decision... And I’m glad I had that time to do that. I think I’m better for having had that time*”. Although women who requested RRM at the point of treatment could recognise the value of a waiting period between treatment and RRM, for many, the outcome of the decision did not change: “*and he said ‘Have you made your decision?’ and I said ‘Yeah.’ I said, ‘It was made from the first time I asked you but, with respect, I knew I had to take that amount of time to, to think about it’*” (participant 9).

Participant 9 appeared aware of the temporal elements and role of justification in her decision-making. For others, this process of justification seemed to occur but was not explicitly stated. Participant 1 talks about the ‘fear’ of finding a lump in her breast and discusses her decision as being driven by fear: “*The fear is always going to be psychological. I think it’s more of a psychological decision that you make*” but later talks about the medical reasons for her decision: “*And that’s another element, being on my right side that, if I found a*

lump and it had already gone to sentinel lymph nodes, I can't have my lymph nodes removed from my arm." (participant 1).

Within the process of justification, women also appeared to draw on their social world, particularly their family and friends to justify their decision, often identifying them as influential in their decision-making process, but again often in the context of also identifying the decision as immediate and personal. Participant 8 illustrates this point. When discussing her decision-making process she states: "... *so straightaway it was like, no, I want them off now. I'm just too terrified of it coming back now.*" And later describes the role that her children, partner and friends played in her decision-making: "*Yeah. I mean I say I think the kids are a big influence to me...because they're the ones like, mum you've got to give it a chance, you know what I mean, you're talking about your life here.*" R: "*was there anyone else that you think played a part in your decision-making at the time?*" P: "*Probably my partner as well... R... So did you, did you discuss your decision with your partner?*" P: "*Yeah, even, even to him it was a no-brainer. You know, so what, you've got to get it done.*" When talking about her friends she says: "*But I think they influenced me as well, 'cause they're all like, you know, if it was me I'd just have them, be gone with them*". The involvement of her family and friends in her decision appeared to have occurred after she had made her decision. Several women emphasised in the interview that their social world more widely agreed with them: "*There is absolutely nobody who disagrees with me, even, um, when I spoke to (name omitted) even she was like, "Oh god", you know. I think everyone's reaction is like, every single person, well female you know, that I have spoken to has gone I would do exactly the same.*" (participant 5).

Discussion

This study used qualitative methods to explore women's decision-making around RRM, particularly the relevance of risk perception and emotion in this process. From analysis of the 12 semi-structured interviews it was suggested that women made their decision to opt for RRM primarily based on a sense of fear, characterised by a sense of menace and the need to do all in their power to reduce their risk. Women then appeared to go through a process of justifying their decision, where the outcome of the decision did not change.

The origins of women's decision-making appear to be the sense of menace that they described. This sense was described in both cognitive (unpredictability and undetectability) and emotional (fear) terms, with the boundaries between the two being unclear. Women were clear that the fear component was important in their decision-making. The nature of this emotional driver appears to differ from the sense of vulnerability that Beesley et al. (2013) reported. The sense of menace was visceral, possibly because cancer was seen as originating within the self and was undetectable. Thus, women felt unable to predict or control the threat. This fear seemed linked to their personal experience of breast cancer, which represented a standard by which to assess risk (Grenning, Dollinger, & Pitz, 1996).

Women also described an imperative to 'do all I can' to prevent reoccurrence. This imperative was important in driving their decision. Indeed, few women reported considering risks of the procedure or indeed the magnitude of risk reduction that could be achieved by RRM. A review of the qualitative literature failed to find a similar construct, suggesting that this belief may be restricted to the context of RRM choice in women who have experienced cancer, but a lack of women in the sample who did not have a personal history of the disease makes conclusions difficult. We speculate that this imperative arises from the intense sense of menace that women felt and their need to act to curtail the threat. This led to a form of

anticipatory guilt (van Dijk, van Roosmalen, Otten, & Stalmeier, 2008) whereby women felt obliged to act to reduce risk.

Women did describe a number of other considerations, such as asking the views of family and clinical staff and considering the pros and cons of the procedure. These are considered justifications because they were not reported as proximal to the decision itself and several women reported that these considerations would not necessarily have made them change their minds. There are two possible functions of justification; they may exist to convince women that they have made sensible and consensual decisions, or they may provide a form of decisional support enabling women to feel more confident in moving toward surgery.

If these are justifications, this appears to contradict research that suggests that women use others to assist with their decision-making process (Howard, Balneaves, Bottorff, & Rodney, 2011). DeVries, Fagerlin, Witteman and Schere (2012) suggest that mental effort is often perceived as a signal that a ‘good’ decision has been made because people believe that mental effort is necessary for effective decision-making and creates a sense of acceptance with the decision outcome.

Relationship to Theory

The finding that decisions to opt for RRM were driven by a sense of menace characterised by high levels of fear contradicts utility theories such as the Health Belief Theory (Hochbaum, 1958) and Protection Motivation Theory (Rogers, 1975, 1983), which propose that people make decisions based on deliberative processing of severity and likelihood of harm.

Women’s denial of the value of statistics and reflection of their decision-making as lacking cognitive reasoning also appears to call into question the role of deliberative processing proposed by dual-processing models. Where deliberative processing was reported it seemed to reflect a process of justification, rather than an integral factor to decision outcome. The

role of emotion appears to play a more central role than that predicted by dual-process models.

The sense of menace described and the suggested relevance of personal experience of breast cancer in creating this sense of menace appear to support Fuzzy Trace Theory ([FTT] Reyna and Adam, 2003). FTT proposes that risk is encoded and represented in terms of general meanings (FTT uses the term ‘gist’) that people abstract from their experiences rather than detailed verbatim representations of reality (e.g., specific risk likelihood estimates). Gists are idiographic and contain both cognitive and emotional components, which, unlike dual process theories, are not seen as separable. FTT suggests that meaning (gist) is actively constructed from experience, the context in which risk-related information is obtained and opportunities to consider and process this information (Reyna, 2004).

Strengths and Limitations

The study limited the sample to women at increased risk of breast cancer who had chosen to opt for RRM. Beyond this however, the inclusion criteria were deliberately broad allowing the population of women choosing RRM at the breast unit to be represented. The heterogeneity in the sample that resulted from these broad inclusion criteria made it possible to identify potential influences on women’s descriptions of their decision-making process by analysing decision processes in women with different experiences. This was particularly valuable because insight provided from the inclusion of one woman who had a personal history of breast cancer provided some contradictions to the wider analysis. This suggests that a personal history of breast cancer influences decision-making. However the ability of the study to explore this issue is limited; inclusion of more women without a personal cancer history would have provided opportunities to consolidate and refine this finding. Additionally, the study describes decision-making in women who opted for RRM, it would be valuable to

contrast this to women who were eligible but opted against RRM. A purposive sampling technique would allow these sampling difficulties to be addressed.

The use of a qualitative methodology allowed the study to gain a rich description of women's personal experiences of decision-making in this area, addressing a gap in current evidence.

However, as with all qualitative research, the study is limited to the information that participants are willing and able to share with the researcher; aspects of the decision-making process which are implicit or otherwise concealed from participants' insights cannot be explored (Knox & Burkard, 2009).

Drawing on widely used and tested methodology through a pragmatic approach to data analysis, the study was able to respond sensitively to the data, whilst retaining rigor. However, unlike more widely used qualitative approaches, the approach adopted lacks predetermined guidelines for implementation that ensure standardised process (Pistrang & Barker, 2012).

However, through group analysis, periodic involvement from the wider research team and detailed analysis note keeping, validity and credibility of the findings was enhanced.

Additionally, through consideration of the emerging findings in relation to clinical and research utility, the study was able to increase catalytic validity and theoretical validity (Kincheloe & McLaren, 2000).

Practical Implications

The findings describe the decision to opt for RRM to be largely driven by a sense of menace in the absence of deliberative consideration of the risk-reducing potential of the procedure or possible side effects. This finding builds on the work of Beesley et al. (2013), showing a tension between accepting autonomous patient decision-making that may not be based on considered thought and utilitarian models of decision-making, which promote rational deliberation of risk.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

There are several options for intervention. First is to try to change women's decision-making processes to fit with utilitarian principles. This may involve decisions aids, which aim to promote deliberative decision-making (De Vries et al., 2013). However, it may be difficult to achieve this, and there is some evidence that intuitive or emotion-based decision-making can actually lead to better decisions (De Vries et al., 2013). A further option may be to attempt to reduce the fear and worry described by women as central to their decision-making process, for example through the provision of psychological therapies. From the data, it seems likely that a therapeutic modality that aims to address the process as opposed to the content of fear and worry, for example metacognitive therapy (Wells & Matthews, 1994), may be useful. However, again it has been argued that affect is an essential component of effective decision-making (De Vries, et al., 2013). Finally, it may be possible to offer an argument that decision-making that draws heavily on affect is a valid decision-making style, with reduction in negative affect, a valid reason for undertaking RRM. Thus, it seems important to understand the advantages and disadvantages of the ways in which women make RRM decisions.

Conclusions

The findings suggest that women's decisions to opt for RRM was driven by a sense of menace, which was characterised by high levels of fear. This menace was translated into action by a belief that they must do all they could to reduce risk. The role of deliberative decision-making occurred later as a process of justification, which did not impact upon decision outcome. Given this understanding, it would now be useful to go further to understand the value of this decision-making style and its implications for decision-making support.

References

- Amir, M., & Ramati, A. (2002). Post-traumatic symptoms, emotional distress and quality of life in long-term survivors of breast cancer: A preliminary research. *Journal of Anxiety Disorders, 16*, 191-206. doi:10.106/S0887-6185(02)00095-6
- Appleton, S., Fry, A., Rees, G., Rush, R., & Cull, A. (2000). Psychosocial effects of living with an increased risk of breast cancer: An exploratory study using telephone focus groups. *Psycho-oncology, 9*, 511–521. doi:10.1002/1099-1611(200011/12)9:63.0.CO;2-E
- Barbour, R. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog? *British Medical Journal, 322*, 1115–1117. doi:10.1136/bmj.322.7294.1115
- Beesley, H., Holcombe, C., Brown, S. L., & Salmon, P. (2013). Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: Analysis of 60 consecutive cases in a specialist breast unit. *Breast, 22*, 179-184. doi:10.1016/j.breast.2012.06.005.
- Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the hospital anxiety and depression scale: An updated literature review. *Journal of Psychosomatic Research, 52*, 69-77. doi:10.1016/S0022-3999(01)00296-3
- Bower, J.E., Ganz, P.A., Desmond, K.A., Rowland, J.H., Meyerowitz, B.E., & Belin, T.R. (2000). Fatigue in breast cancer survivors: Occurrence, correlates and impact on quality of life. *Journal of Clinical Oncology, 18*, 743–753.
- Bradley, C. J., Bednarek, H. L., & Neumark, D. (2002). Breast cancer survival, work, and

earnings. *Journal of Health Economics*, 21, 757-779. doi: 10.1016/S0167-6296(02)00059-0

Cancer Research UK. (2013). *Breast Cancer Key Facts*. Retrieved from:

<http://www.cancerresearchuk.org/cancer-info/cancerstats/keyfacts/breast-cancer/cancerstats-key-facts-on-breast-cancer>.

Chamberlain, K. (2000). Methodolatry and qualitative health research. *Journal of Health Psychology*, 5, 285-296.

De Vries, M., Fagerlin, A., Witteman, H. O., & Scherer, L. D. (2013). Combining deliberation and intuition in patient decision support. *Patient Education and Counseling*, 91, 154-160. doi: 10.1016/j.pec.2012.11.016

Drife, JO. (1992). Are breasts redundant organs? *British Medical Journal*, 304:1060.

Frost, M. H., Schaid, D. J., Sellers, T. A., Slezak, J. M., Arnold, P. G., Woods, J. E., ... & Hartmann, L. C. (2000). Long-term satisfaction and psychological and social function following bilateral prophylactic mastectomy. *The Journal of the American Medical Association*, 284, 319-324. doi:10.1001/jama.284.3.319.

Frost, M. H., Slezak, J. M., Tran, N. V., Williams, C. I., Johnson, J. L., Woods, J. E., ... & Hartmann, L. C. (2005). Satisfaction after contralateral prophylactic mastectomy: The significance of mastectomy type, reconstructive complications, and body appearance. *Journal of Clinical Oncology*, 23, 7849-7856. doi: 10.1200/JCO.2005.09.233

Gabriel, S. E., Woods, J. E., O'Fallon, W. M., Beard, C. M., Kurland, L. T., & Melton, L. J. (1997). Complications leading to surgery after breast implantation. *New England Journal of Medicine*, 336, 677-682.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- Greening, L., Dollinger, S. J., & Pitz, G. (1996). Adolescents' perceived risk and personal experience with natural disasters: An evaluation of cognitive heuristics. *Acta Psychologica*, 91, 27-38. doi: 10.1016/0001-6918(94)00040-9
- Gwyn, R. (2002). *Communicating Health and Illness*. London: Sage Publications.
- Hawkes, G., & Rowe, G. (2008). A characterisation of the methodology of qualitative research on the nature of perceived risk: Trends and omissions. *Journal of Risk Research*, 11, 617-643. doi:10.1080/13669870701875776
- Hochbaum, G. M. (1958). Public participation in medical screening programs: A socio-psychological study. Public Health Service publication. Washington, D.C.
- Hopwood, P., Lee, A., Shenton, A., Baildam, A., Brain, A., Lalloo, F., ... & Howell, A. (2000). Clinical follow-up after bilateral risk reducing ('prophylactic') mastectomy: mental health and body image outcomes. *Psycho-Oncology*, 9, 462-472. doi: 10.1002/1099-1611(200011/12)9:6<462::AID-PON485>3.0.CO;2-J
- Hoskins, L. M., Roy, K. M., & Greene, M. H. (2012). Toward a new understanding of risk perception among young female BRCA1/2 "previvors". *Families Systems & Health*, 30, 32-46. doi:10.1037/a0027276
- Howard, A., Balneaves, L., & Bottorff, J. (2009). Women's decision making about risk-reducing strategies in the context of hereditary breast and ovarian cancer: A systematic review. *Journal Of Genetic Counseling*, 18, 578-597. doi:10.1007/s10897-009-9245-9
- Howard, A., Balneaves, L., Rodney, P., & Bottorff, J. (2011). Preserving the self: The process of decision making about hereditary breast cancer and ovarian cancer risk reduction. *Qualitative Health Research*, 21, 502-519. doi:10.1177/1049732310387798

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- Katapodi, M. C., Lee, K. A., Facione, N. C., & Dodd, M. J. (2004). Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: A meta-analytic review. *Preventive Medicine*, 38, 388-402.
doi:10.1016/j.ypmed.2003.11.012
- Kincheloe, J., McLaren, P. (2000). *Rethinking critical theory and qualitative research*, (2nd ed.), CA; London: Sage.
- Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. In J. Ritchie, & J. Lewis (Eds.), *Qualitative research practice: A guide for social science students and researchers* (pp. 138-169). London: Sage.
- Lostumbo, L., Carbine, N., Wallace, J., & Ezzo, J. (2004). Prophylactic mastectomy for the prevention of breast cancer. *Cochrane Database Systematic Reviews*, Issue 4. Art. No.: CD002748. doi:10.1002/14651858.CD002748.pub2
- Meiser, B., Butow, P., Friedlander, M., Schnieden, V., Gattas, M., Kirk, J., ... & Tucker, K. (2000). Intention to undergo prophylactic bilateral mastectomy in women at increased risk of developing hereditary breast cancer. *Journal of Clinical Oncology*, 18, 2250-2257.
- National Institute of Clinical Excellence. (2013). *Familial breast cancer: Classification and care of people at risk of familial breast cancer and management of breast cancer and related risks in people with a family history of breast cancer*. Retrieved from <http://www.nice.org.uk/guidance/index.jsp?action=byID&o=14188>
- Payne, D. K., Biggs, C., Tran, K., Borgen, P. I., & Massie, M. J. (2000). Women's regrets after bilateral prophylactic mastectomy. *Annals of Oncology*, 7, 150-154.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Peters, E., McCaul, K. D., Stefanek, M., & Nelson, W. (2006). A heuristics approach to understanding cancer risk perception: Contributions from judgment and decision-making research. *Annals Of Behavioral Medicine*, 31, 45-52.

doi:10.1207/s15324796abm3101_8

Pistrang, N., & Barker, C. (2012). Varieties of qualitative research: A pragmatic approach to selecting methods. In H. Cooper, P. Camic, D. Long, A.T. Panter, D. Rindskop, K.J. Sher (Eds.), *APA handbook of research methods in psychology* (pp. 5-18). doi: 10.1037/13620-001

Rebbeck, T. R., Friebe, T., Lynch, H.T., Neuhausen, S.L., van't Veer, L., Garber, J.E.,...Weber, B.L. (2004). Bilateral prophylactic mastectomy reduces breast cancer risk in *BRCA1* and *BRCA2* mutation carriers: The PROSE study group. *Journal of Clinical Oncology*, 22, 1055–1062. doi: 10.1200/JCO.2004.04.188

Reyna, V. F. (2004). How people make decisions that involve risk: A dual-processes approach. *Current Directions in Psychological Science*, 13, 60-66. doi:10.1111/j.0963-7214.2004.00275.x.

Reyna, V. F., & Adam, M. B. (2003). Fuzzy- trace theory, risk communication, and product labeling in sexually transmitted diseases. *Risk Analysis*, 23, 325-342. doi:10.1111/1539-6924.00332

Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change. *Journal of Psychology*, 91, 93-114.

Rogers, R.W. (1983). Cognitive and physiological processes in fear appeals and attitude change: A revised theory of protection motivation. In J. Cacioppo & R. Petty (Eds.), *Social Psychophysiology* (pp.153-177). New York: Guilford Press.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Salmon, P. (2003). How do we recognise good research?, *Psychologist*, 16, 24-27.

Salmon, P., Mendick, N., & Young, B. (2011). Integrative qualitative communication analysis of consultation, patient and practitioner perspectives: Towards a theory of authentic caring in clinical relationships. *Patient Education and Counseling*, 82, 448-454. doi: 10.1016/j.pec.2010.10.017

Seale, C. (1999). Quality in qualitative research. *Qualitative Inquiry*, 5, 465-478.

Sestak, I., Cuzick, J., Evans, D.G, & Kwong, A. (2012). Prevention of breast cancer. In Dixon, M.J. (Ed.), *ABC of Breast Diseases* (pp. 47-50). Chicago: Wiley-Blackwell.

Snaith, R. P., & Zigmond, A. S. (1994). *HADS: Hospital Anxiety and Depression Scale*. Windsor: NFER Nelson.

Stefanek, M.E, Helzlsouer, K.J., Wilcox, R.N., Houn, F. (1995). Predictors of and satisfaction with bilateral prophylactic mastectomy. *Preventative Medicine*, 24, 412-419.

Stefanek, M., Hartmann, L., & Nelson, W. (2001). Risk-reduction mastectomy: Clinical issues and research needs. *Journal of the National Cancer Institute*, 93, 1297-1297. doi: 10.1093/jnci/93.17.1297

Sivell, S., Elwyn, G., Edwards, A., Gaff, C., Clarke, A., Iredale, R., & ... Thornton, H. (2008). How risk is perceived, constructed and interpreted by clients in clinical genetics, and the effects on decision making: Systematic review. *Journal Of Genetic Counseling*, 17, 30-63. doi:10.1007/s10897-007-9132-1

Stiles, W. B. (1993). Quality control in qualitative research. *Clinical Psychology Review*, 13, 593-618.

Stiles, W. B. (1999). Evaluating qualitative research. *Evidence Based Mental Health*, 2, 99-101.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

van Dijk, S., Otten, W., Zoetewij, M., Timmermans, D., van Asperen, C., Breuning, M., & ...

Kievit, J. (2003). Genetic counselling and the intention to undergo prophylactic mastectomy: Effects of a breast cancer risk assessment. *British Journal Of Cancer*, 88, 1675-1681. doi:10.1038/sj.bjc.6600988

van Dijk, S., van Roosmalen, M. S., Otten, W., & Stalmeier, P. F. (2008). Decision making regarding prophylactic mastectomy: stability of preferences and the impact of anticipated feelings of regret. *Journal of Clinical Oncology*, 26, 2358-2363. doi: 10.1200/JCO.2006.10.5494

Weinstein, N. D. (1980). Unrealistic optimism about future life events. *Journal of Personality and Social Psychology*, 39, 806. doi: 10.1037/0022-3514.39.5.806

Weinstein, N.D. (1993) Testing four competing theories of health-protective behavior. *Health Psychology*, 12, 324–333.

Wells, A. & Matthews G. (1994). *Attention and Emotion: A Clinical Perspective*. Hove, UK: Erlbaum.

Wright, E. B., Holcombe, C., & Salmon, P. (2004). Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *British Medical Journal*, 328, 864-869. doi:10.1136/bmj.38046.771308.7C

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.

Zigmond, A. S., & Snaith, R. P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, 67, 361-370.

Appendices

Appendix Number	Title	Page Number
Appendix 1	Author guidelines: <i>Health Psychology Review</i>	69
Appendix 2	Scoping searches / Process Notes	70-75
Appendix 3	CASP Assessment Tool	76
Appendix 4	Author Guidelines: <i>Journal of Psychology and Health</i>	77
Appendix 5	Participant information sheet	78-81
Appendix 6	Further Study Details	82-89
Appendix 7	Participant Consent form	90-91
Appendix 8	Demographic Information Collection Sheet	92
Appendix 9	Hospital Anxiety and Depression Scale	93
Appendix 10	Interview Guide (with refinements)	94-96
Appendix 11	Dealing with distress protocol	97
Appendix 12	Data Protection Protocol	98-99
Appendix 13	Example Vignette	100
Appendix 14	Example of summary of analysis	100-101
Appendix 15	Example of Initial Analysis (for fear/ vulnerability)	102-104
Appendix 16	Example data analysis- conceptual categories (Fear/ vulnerability)	105

Appendix 1: Author guidelines: *Health Psychology Review*

Manuscripts are accepted in English. British English spelling and punctuation are preferred.

Taylor & Francis Standard Reference Style: APA 6th Edition

Articles to *Health Psychology Review* should therefore be no longer than 30 double-spaced manuscript pages. Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list). Abstracts of 200 words are required for all manuscripts submitted.

Each manuscript should have 3 to 6 keywords.

In order to comply with international standards and for academic transparency, authors of meta-analyses and systematic reviews submitted to *Health Psychology Review* are required to include a statement in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (<http://www.prisma-statement.org/>).

Appendix 2: Scoping searches / Process Notes

Search Strategy 1

“Breast Cancer” OR “Breast neoplasm” OR “Breast Carcinoma” AND “increased risk” OR “elevated risk” OR “high risk” OR “moderate risk” OR brca*1 OR brca*2 OR tp53 OR “genetic risk” OR “hereditary risk” OR inherit* OR familial OR Ashkenazi AND “Risk perception” OR “Risk understanding” OR “Perceived risk” OR Worry OR Dread OR “Anticipated emotion” OR “Anticipatory emotion” OR Affect OR Emotion* OR Vulnerability AND increased risk OR “elevated risk” OR “high risk” OR “moderate risk” OR brca*1 OR brca*2 OR tp53 OR genetic risk OR hereditary risk OR inherit* OR familial OR Ashkenazi

Reflection: Specific to increased risk = too restrictive (search by hand?)

Search Strategy 2

“Breast Cancer” OR “Breast neoplasm” OR “Breast Carcinoma” AND “increased risk” OR “elevated risk” OR “high risk” OR “moderate risk” OR brca*1 OR brca*2 OR tp53 OR “genetic risk” OR “hereditary risk” OR inherit* OR familial OR Ashkenazi AND “Risk perception” OR “Risk understanding” OR “Perceived risk” OR Worry OR Dread OR “Anticipated emotion” OR “Anticipatory emotion” OR Affect OR Emotion* OR Vulnerability

Reflection: Papers not particularly relevant. Search qualitative papers only.

Final Search Strategy

1- “breast cancer” OR “breast carcinoma” OR “breast neoplasm”

AND

2- “risk perception” OR “risk understanding” OR “perceived risk” OR worry OR

**dread OR “anticipated emotion” OR “anticipatory emotion” OR affect OR
emotion* OR vulnerability**

AND

**Qualitative OR “Grounded theory” OR IPA OR “Interpretative Phenomenological
Analysis” OR “Thematic analysis” OR “Content analysis” OR “Narrative analysis” OR
“Conversation analysis” OR “Narrative analysis” OR “Discourse analysis” OR
Interview* OR Observation OR “Focus groups”**

Table 1:

Example of full search and record of number of results per search term (Psych INFO)

Word	Hits
“Breast Cancer”	7781
“Breast Carcinoma”	70
“Breast neoplasm”	4
“Breast Cancer” OR “Breast neoplasm” OR “Breast Carcinoma”	7818
“Risk perception”	5209
“Risk understanding”	37
“Perceived risk”	2237
Worry	7789
Dread	778
“Anticipated emotion”	21
“Anticipatory emotion”	1
Affect	157393
Emotion*	285272
Vulnerability	24474
“Risk perception” OR “Risk understanding” OR “Perceived risk” OR Worry OR Dread OR “Anticipated emotion” OR “Anticipatory emotion” OR Affect OR Emotion* OR Vulnerability	442486
Qualitative	87,429
“Grounded theory”	8,638

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

IPA	943
“Interpretative Phenomenological Analysis”	786
“Thematic analysis”	3252
“Content analysis”	15,003
“Narrative analysis”	1264
“Conversation analysis”	1163
“Narrative analysis”	1264
“Discourse analysis”	7763
Interview*	208514
Observation	101276
“Focus groups”	10921
Qualitative OR “Grounded theory” OR IPA OR “Interpretative Phenomenological Analysis” OR “Thematic analysis” OR “Content analysis” OR “Narrative analysis” OR “Conversation analysis” OR “Narrative analysis” OR “Discourse analysis” OR Interview* OR Observation OR “Focus groups”	360788
“Breast Cancer” OR “Breast neoplasm” OR “Breast Carcinoma” AND “Risk perception” OR “Risk understanding” OR “Perceived risk” OR Worry OR Dread OR “Anticipated emotion” OR “Anticipatory emotion” OR Affect OR Emotion* OR Vulnerability AND Qualitative OR “Grounded theory” OR IPA OR “Interpretative Phenomenological Analysis” OR “Thematic analysis” OR “Content analysis” OR “Narrative analysis” OR “Conversation analysis” OR “Narrative analysis” OR “Discourse analysis” OR Interview* OR Observation OR “Focus groups”	522
“Breast Cancer” OR “Breast neoplasm” OR “Breast Carcinoma” AND “Risk perception” OR “Risk understanding” OR “Perceived risk” OR Worry OR Dread OR “Anticipated emotion” OR “Anticipatory emotion” OR Emotion* OR Vulnerability AND Qualitative OR “Grounded theory” OR IPA OR “Interpretative Phenomenological Analysis” OR “Thematic analysis” OR “Content analysis” OR “Narrative analysis” OR “Conversation analysis” OR “Discourse analysis” OR Interview* OR “Focus groups”	443
	417 English

Note. Database searched PschINFO; date searched 11/10/2013; terms searched article, title, abstract, keyword (any field)

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Table 2:

Total combined search by database

Database	Results
PsychINFO	417
Scopus	666
Web of Knowledge	1026
Medline	555
Hand Searching	15
Total	2679

Table 3:

Number of studies excluded at each point

Point of exclusion	Total removed	Total remaining
Duplicates	1351	1328
Title	284	1044
Abstract	922	122
Full text	108	16

Table 4:

Exclusion from title

Reason	Number
Sample	282
Methodology	1
Type	1

Table 5:

Exclusion from abstract

Reason	Number
Sample	380
Topic	323
Methodology	183

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Type	27
Duplicates not previously identified	9

Table 6:

Exclusion from full text

Reason	Number
Sample	31
Topic	47
Methodology	6
Type	12
Duplicates not previously identified	2
Unable to access	8

Table 7:

Reasons for exclusion

Main Reason	Examples
Sample	Carer Child Current BC Male Not Breast cancer/ not only BC Professional sample Not increased risk/ population
Method	Quantitative Single case study Forced choice interview RP as %
Type	Review Dissertation Critique of a book Poster

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

	Book
	Editorial/ position paper
Topic	Not womens' experience
	Not specific to BC
	Not investigating women's risk perception

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Appendix 3 CASP Assessment Tool

Table 1:

Quality rating using CASP tool

	Altschuler & Somkin (2005)	Beesley, Holcombe, Brown & Salmon (2013)	Bennett, Parsons, Brain, & Hood (2010)	Chalmers, & Thomson (1996)	Dagan, & Goldblatt, (2009)	Hallowell, Foster, Eeles, Ardern-Jones, & Watson (2004)	Hoskins, Roy, & Greene (2012)	Kelly (1980)	Kenen, Ardern- Jones, & Eeles (2003)	Keogh, McClare n, Apicella & Hopper (2011)	Raveis & Pretter (2005)	Roberts on (2000)	Sheinfel d Gorin, Albert (2003)	Werne r- Lin (2007)
Was there a clear statement of the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Is a qualitative methodology appropriate?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the research design appropriate to address the aims of the research?	Y	Y	N	N	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Was the recruitment strategy appropriate to the aims of the research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was the data collected in a way that addressed the research issue?	Y	N/A	Y	Y	Y	Y	Y	N	Y	Y	Y	Y	N	Y
Has the relationship between researcher and participants been adequately considered?	N	N	N	N	Y	N	Y	Y	Y	N	N	N	N	N
Have ethical issues been taken into consideration?	N	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	N	Y	N
Was the data analysis sufficiently rigorous?	Y	Y	N	Y	Y	Y	Y	N	N	Y	Y	N	Y	Y
Is there a clear statement of findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
How valuable is the research?	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable	Valuable

Appendix 4: Author Guidelines

Empirical: *Journal of Psychology and Health*

Aims and Scope: Psychology & Health promotes the study and application of psychological approaches to health and illness. The contents include work on psychological aspects of physical illness, treatment processes and recovery; psychosocial factors in the aetiology of physical illnesses; health attitudes and behaviour, including prevention; the individual-health care system interface particularly communication and psychologically-based interventions. The journal publishes original research, and accepts not only papers describing rigorous empirical work, including meta-analyses, but also those outlining new psychological approaches and interventions in health-related fields.

Manuscripts are accepted in English. British English spelling and punctuation are preferred. A typical manuscript will not exceed 30 pages including tables, references, captions and endnotes. Manuscripts that greatly exceed this will be critically reviewed with respect to length. Authors should include a word count with their manuscript.

Manuscripts should be compiled in the following order: title page; abstract; keywords; main text; acknowledgements; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Abstracts of 200 words are required for all manuscripts submitted.

Each manuscript should have 3 to 6 keywords.

Taylor & Francis Standard Reference Style: APA 6th Edition

Appendix 5: Participant information sheet

Trust Information Removed



Patient Information Sheet

Patient and surgeon decision-making in risk-reducing mastectomy: an ethical and empirical analysis

1

You are being invited to take part in a research study. Before you decide to take part or not, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

We are interested to learn how women make decisions about whether to have a risk-reducing mastectomy or not. We are also interested in how clinical staff help them to make their decisions and how they see their role in the decision process. We hope that our findings will help us to understand how clinicians can best help women to make decisions in future.

Why have I been chosen?

You have been asked to take part in the study because we understand that you have considered having a risk-reducing mastectomy (Breast Unit name) at (location).

Do I have to take part?

You do not have to take part in this study. It is up to you to decide whether or not to take part. If you decide to take part, you will be given this Information Sheet to keep and will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Whether you participate or not will not affect the care you receive. If you were to participate but then withdraw, this would not affect the care you receive either.

What will happen to me if I take part?

If you choose to take part, you will be given a copy of this Information Sheet and a signed Consent Form to keep.

We would like to interview you about how you have thought about the possibility of having this operation and how you decided about it. In particular, we are interested in how you thought and felt about the risk of cancer and risk-reducing mastectomy and how you and your clinician came to decide about what is best to do. You can choose whether you would prefer to be interviewed at the (Breast Unit) at the University of Liverpool or at your own home. If you choose to be interviewed at the Breast Unit name or the University of Liverpool, your travel expenses will be paid.

- Your interview will be audio-recorded if you agree to this. The length of the interview will vary, depending on how much you wish to talk about. However, the interview is likely to last between 20 minutes and 60 minutes.
- The audio-recordings of the interview will be typed up by the researcher. All information which might identify you will be removed and replaced by a code so that any personal information (such as names, addresses, doctors' names etc.) will not be included in the research.
- The interview will focus on the following topics: how you viewed the risk of breast cancer (re)occurrence, how you first became aware of the possibility of having a risk-reducing mastectomy, the factors that contributed to your preferences to have the risk-reducing mastectomy or not and how you and the clinical staff interacted to make the decision.
- With your permission, we would also like to interview clinical staff who have been involved in this decision. None of the interviewees will be told what any other interviewee has told us.

What are the possible disadvantages of taking part?

The interview may involve talking about information that was or is upsetting for you. However, you do not have to talk about anything you do not wish to. If you feel that you need help with any of the matters that we have discussed one of the research team will be happy to speak to you to give you advice on further sources of support.

What are the possible benefits of taking part?

You will not personally benefit from taking part in the study. However, any information that you give us can help us find out more about how people make this decision and about the roles that clinical staff should play. We hope that our findings will help clinicians to be more effective in helping women in future.

What if something goes wrong?

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms will be available to you. You can complain to:

Customer Relations Team
(name)
Address
Email

(name) Hospital Patient Quality team (contact number)

Will my taking part in this study be kept confidential?

All data collected for this study will be kept safely and securely on computer and on transcribed paper records. (Chief investigator name) will be the custodian of all study data. All information about you will be confidential. Any information which identifies you (for example, your name, names of family, friends, and doctors, addresses, names of hospitals, telephone numbers, date of birth, and employment) will be removed from transcriptions and replaced by a code.

What will happen when the study ends?

After all identifying details have been removed from the transcribed records of consultations and interviews, these will be analysed by the study team. The results will be published in reports and scientific journals, but it will not be possible to identify any individuals from these reports. Any quotation used in the writing up of the final study will be kept anonymous.

With your permission, transcripts of audio recordings of interviews and consultations will be stored at the University of Liverpool for 10 years after the end of this study for possible use in future studies. If you consent to it, a printed transcript of the interview will be offered to UK Data Archive where it will be made available to future researchers. All information that might enable you to be recognised will be removed from these records

What will happen to the results of the research study?

The clinical psychology student who is part of the team will write up the results of the study for for the Degree of Doctor of Clinical Psychology. This thesis will be kept in the library of the Division of Clinical Psychology, University of Liverpool. A copy of this thesis will also be kept in the University's Library. After the interview, you can ask if you would like a summary of these results, which will then be available after October 2014. You will not be identified in these results.

We will also write the results up to publish them in academic journals. After the interview, you can also ask if you would like a copy of these publications. You will not be identified in any publications.

Who is organizing and funding the research?

The chief investigator is (name), a senior lecturer at Liverpool University. He is collaborating with (names). (name) is employed as a Research Officer to conduct the research, and (name) is a student in Clinical Psychology who is conducting the research as part of her qualification.

The Economic and Social Research Council is funding the research.

Who has reviewed the study?

The study has been reviewed by:

- The Department of Psychological Sciences at Liverpool University
- The Economic and Social Research Committee
- (name) Local Research Ethics Committee.

Contact information

(name) Chief investigator

Contact address

Tel: (contact number)

Email: (contact email)

For independent advice please contact:

Patient Advice and Liaison Service

Contact

Contact

Appendix 6: Further Study Details

Location within the Wider Study

This research was part of a wider study titled: Patient and surgeon decision-making in risk-reducing mastectomy: An ethical and empirical analysis, conducted by staff at the University of Liverpool. The larger study aimed to investigate and triangulate patient and surgeon decision-making and draw conclusions regarding the quality of decision-making. This research aimed to specifically explore women's decision-making with particular focus on the role of risk perception and emotion and the links with current theory and practice. The trainee was involved in the initial design of the study and reviewed the ethics application, participant information sheets and the interview guide. The trainee was involved in all aspects of data collection and analysis. Analysis was completed within the team; analysis of the aspects relevant to this study was led by the trainee. Data presented within this study will inform the analysis of the wider study (alongside data provided from surgeon interviews).

Procedure and Ethics

An overview of the procedure and ethics is provided in the main text, additional information is offered to allow a more detailed assessment of quality. The wider study received approval by the local NHS Research Ethics committee (13/NW/0421) and sponsorship from University of Liverpool (UoL000957). Approval was received for the trainee to be involved in the study. Details of the trainee and supervisors' previous research and academic experience were provided to evidence that the researchers were competent to complete the study.

Acknowledgement that interviewing could influence decision-making and the ethical difficulties associated with this, resulted in restriction of inclusion to women who did not plan to revisit their decision for the three months subsequent to the interview. Recognition of

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

the possible effect of length of time since surgery on recall of the decision-making process resulted in exclusion of women over 3 months post-surgery.

Consent to retain identifying information for the duration of the study was obtained, preventing women who had previously participated being approached again and enabling the provision of feedback of the results if requested. Identifying details of women who had declined participation were not collected as consent to do so had not been provided. Clinical staff were asked not to approach women who they knew to have previously declined to participate.

To ensure adequate time to consider participation, potential participants were contacted one week after provision of the information sheet. The participant information sheet contained all relevant ethical information and this information was verbally reiterated prior to written consent being obtained and completion of the interview. All participant information (verbal and written) was provided in easily accessible, everyday language.

Participants were informed that all information would be anonymous unless there was concern for their safety or the safety of others (see dealing with distress policy, appendix 11). There were no cases that necessitated anonymity to be broken. Participants were informed that their case would be discussed with clinical care staff (for the purpose of the wider study), but that information provided during the course of the interview would not be discussed, unless anonymously. Women were assured that completion of the study was entirely voluntary and would not impact on their care. Participants were informed of their right to withdraw or remove their data at any point without negative consequence. One participant chose to remove a section of the data she had provided. Following the interview participants were afforded the opportunity to ask question and their attention was drawn to the contact details for the study on the information sheet. Interviews were conducted at a location

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

convenient for participants (home, hospital, work). In order to maximise the safety of the researchers University lone working policy was adhered to.

Management of data was detailed in a data protection protocol (appendix 12), created prior to the start of data collection. Data were recorded on a digital recorder and transferred to a secure computer file store and removed from the recorder at the earliest opportunity. An independent transcription company, who were required to sign a confidentiality agreement, transcribed all audio recordings. Following consistency checks and removal of any potential identifying information, audio recordings were deleted. Anonymised transcripts were emailed to the core research team for analysis. Participants were informed that the University of Liverpool would store an anonymised transcript of the interview for up to ten years, after which it would be destroyed. The data custodian (principle investigator) was responsible for ensuring that data were destroyed after the adequate time period. Anonymised demographic information was kept and linked to interviews by a participant identification number. Signed consent forms were kept for the duration of the study. All digital information was stored on University computers within a secure file store that only the core research team had access to. All identifying written information was stored in a locked cabinet on university premises and will be destroyed following completion of the wider study.

Epistemology and Methodology

The research questions posed necessitated a qualitative approach. As detailed, the research took a pragmatic approach to data analysis similar to that advocated by Gwyn (2002), allowing a range of methodologies and epistemological positions to be drawn upon as required by the data, examples of which are provided. The use of pluralist qualitative research is increasing and guidance is now available about how to conduct such research in a rigorous and valid way (e.g. Frost, 2011).

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

The research initially attempted to understand how women made decisions regarding RRM by how they attempted to convey understanding of their internal world (and decision-making process) directly through the language that they used, a largely positivist frame. Use of thematic analysis (from a largely positivist position) allowed recognition of recurrent features of women's accounts, for example frequent use of the term 'fear' in relation to breast cancer occurrence and informed the findings in which fear was hypothesised to drive decision-making.

However, the role of context in which these discussions were framed, was also recognised, an interpretative social constructionist position. Despite recognition that women conveyed meaning through the language they used, the interviews were not regarded as always providing direct access to participants' experiences and intentions, but were interpreted within the interview and wider social context. Understanding at the level of individual sections of text was combined with awareness and discussion of the whole interview and field notes, particularly when there were contradictions in the narrative and times when the content appeared to reflect justification rather than explanation. Drawing on discourse analysis, women's emotive language such as frequent reference to others agreeing with their decision was hypothesised as women justifying their decision to opt for RRM (to the self and the interviewer), possibly due to a negative discourse around mastectomy. This also allowed the contradiction in the narratives to be recognised. For example, women would often identify the decision to be personal and driven by fear and then identify the role of others in the decision-making. This understanding allowed recognition of the role of 'justification' in the model, an understanding that may not have been reached within a purely positivist frame. The potential for pre-decisional processes to be mis-remembered and reconstructed in the light of the decisions or 'altered' to fit a preferred interpretation (Yardley, 2000) was also reflected on and discussed throughout the analysis process.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Support for the value of the analysis used comes from a number of published studies conducted by members of the research team (e.g. Salmon, Mendick, & Young, 2011; Wright, Holcombe, & Salmon, 2004). Experience and expertise within the core research team were drawn upon throughout the analysis process to ensure that this procedure was rigorous and done in a way that ensured validity.

Reflexivity

Reflexivity is important in research; perhaps even more so in pluralist qualitative research (Frost, 2011). The researcher had little experience with breast cancer prior to completing the research. However, it is possible that the fact that the researcher was a woman may have impacted upon the information participants provided and also how it was interpreted. It is possible that the researchers consideration of herself in the position of the participants and the actions she feel she may take may have influenced how she interacted with the participants and the interpretation.

It was considered whether participants placed the researcher in a position of a 'health professional' (despite description of the role of the researcher). Evidence for this comes from one participant asked questions about her health care. It is possible that being placed in this position may have influenced the information that the women provided. It is possible that women felt the need to justify their decision and highlight it as rationale more so than if they regarded the researcher as independent. Further, one woman talked about feeling 'grateful to the NHS', it is useful to consider whether this would be the case if the researcher was viewed as completely independent.

Awareness of these potential influences alongside group analysis and discussion was helpful in addressing personal biases and influences.

Quality and Validity

The way in which the validity of qualitative research is judged is a contentious topic, with some suggesting that qualitative research can be assessed in a way similar to quantitative, albeit with related but different concepts, leading to the development of a number of checklists to assist with the assessment of quality (CASP, 2013). However, some suggest that the expectation that validity can be assessed in much the same way as quantitative methods is ‘absurd’ and others are critical of the use of ‘technical fixes’, suggesting that the use of techniques such as triangulation and multiple coding does not in itself confer rigour (Barbour, 2001; Salmon, 2003). In an effort to address these criticisms, a detailed account of all aspects of data collection and analysis is provided (in the main text and above) in order to permit others to judge quality (Patton, 1999), alongside a further discussion of various aspects pertaining to quality and validity.

Dependability

In an effort to make the research transparent and dependable, detailed records of data analysis meetings and discussion relevant to the research project were kept, provide an audit trail that is available for review if required. Documents at various stages of refinement (e.g. analysis documents and interview schedules) are also available and examples of each have been provided. Discussion of other aspects of research quality (e.g. credibility, confirmability) also increase the dependability of the findings.

Credibility

Transcripts were initially coded by each member of the core research team (multiple coding) and brought together at an analysis meeting. Disagreements were encouraged, discussed and explored allowing alternative explanations to be fully explored and analysis to be refined.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Further confirmation was sought from members of the wider research team (peer review) made up of various health professional positions (psychologist, surgeon, nurse). Regular discussion of how analysis fit with and contradicted existing theory (triangulation) also supported credibility of the findings (Huberman & Miles, 1994). Credibility is further ensured through provision of detailed description of findings and detailed quotes.

Generalisability

Attempts to characterise the sample through demographic and psychometric (HADS) information, alongside description of study participants and setting allows an evaluation of the transferability of findings to other settings. Discussion of the context in which the findings were positioned (see analysis section above) provides further information relevant to assessing generalisability.

Bias

Throughout the research process, there was explicit recognition by members of the research team about the position of the research following on from Beesley, Holcombe, Brown and Salmon (2013) and the potential for the research to pursue these initial conclusions (Silverman, 2000). This awareness and continuous efforts to falsify the emerging analysis provided a safeguard against this.

References

- Barbour, R. S. (2001). Checklists for improving rigour in qualitative research: A case of the tail wagging the dog?. *British Medical Journal*, 322, 1115.
- Beesley, H., Holcombe, C., Brown, S. L., & Salmon, P. (2013). Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: Analysis of 60 consecutive cases in a specialist breast unit. *Breast*, 22, 179-184.

doi:10.1016/j.breast.2012.06.005.

Critical Appraisal Skills Programme. (2013). Critical Skills Appraisal Program: Qualitative Research Checklist 31.05.13. Retrieved from www.casp-uk.net

Frost, N. (2011). *Qualitative research methods in: Combining core approaches*. Maidenhead: McGraw-Hill.

Gwyn, R. (2002). *Communicating Health and Illness*. London: Sage Publications.

Huberman, M., & Miles, M. B. (Eds.). (1994). *The qualitative researcher's companion*. London: Sage Publications.

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. *Health Services Research, 34*, 1189.

Salmon, P. (2003). How do we recognise good research. *The Psychologist, 16*, 24-27.

Salmon, P., Mendick, N., & Young, B. (2011). Integrative qualitative communication analysis of consultation, patient and practitioner perspectives: Towards a theory of authentic caring in clinical relationships. *Patient Education and Counseling, 82*, 448-454. doi: 10.1016/j.pec.2010.10.017

Silverman, D. (2000). *Doing qualitative research*. London: Sage Publications.

Wright, E. B., Holcombe, C., & Salmon, P. (2004). Doctors' communication of trust, care, and respect in breast cancer: qualitative study. *British Medical Journal, 328*, 864-869. doi:10.1136/bmj.38046.771308.7C

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*, 215-228.

Appendix 7: Participant Consent form

Trust Information Removed



Centre Number:

Participant Identification Number for this study:

Patient Consent Form

Title of Project:

Patient and surgeon decision-making in risk-reducing mastectomy: an ethical and empirical analysis

Name of researcher: _____

Please initial box

1. I confirm that I have read and understand the information sheet dated (version) for the above study. I have had the opportunity of consider the information, ask questions and have these answered satisfactorily.		
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.		
3. I understand that audio recordings will be made as part of this study, and that brief quotations from some interviews or consultations may be included in study reports. I understand nobody will be able to identify me in these reports.		
4. I agree to anonymous records of my interview being stored at the University of Liverpool for up to 10 years after the end of this study.	Yes	No
5. I agree to one or more staff who have participated in my decision being interviewed. I understand that no details of what I have said will be made known to them.	Yes	No
6. I agree to an anonymous transcript of my interview being held by the UK Data Archive and this being available to other researchers registered with UK Data Archive.	Yes	No
7. I would like to receive a summary of the findings at the end of the study.	Yes	No
8. I agree to take part in the above study.		

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Name of participant

Date

Signature

Name of researcher

Date

Signature

Appendix 8: Demographic information collection sheet**Risk-reducing Mastectomy Study: Demographics Form**

Participant ID:

Age (please tick):	16-20 <input type="checkbox"/> 21-25 <input type="checkbox"/> 26-30 <input type="checkbox"/> 31-35 <input type="checkbox"/> 36-40 <input type="checkbox"/> 41-45 <input type="checkbox"/> 46-50 <input type="checkbox"/> 51-55 <input type="checkbox"/> 56-60 <input type="checkbox"/> 61-65 <input type="checkbox"/> 66-70 <input type="checkbox"/> 70+ <input type="checkbox"/>
Education (please tick highest qualification):	GCSEs or equivalent <input type="checkbox"/> NVQ <input type="checkbox"/> A-Levels or equivalent <input type="checkbox"/> Bachelor's degree <input type="checkbox"/> Post-graduate degree <input type="checkbox"/>
Employment status (please tick):	Unemployed <input type="checkbox"/> Long-term sick <input type="checkbox"/> Part-time <input type="checkbox"/> Full-time <input type="checkbox"/>
Previous breast cancer (please tick):	Yes <input type="checkbox"/> No <input type="checkbox"/>
Time since diagnosis of breast cancer (if applicable):	_____ <input type="checkbox"/>
Time since end of treatment for breast cancer (if applicable):	_____
BRCA 1/2 status	Positive <input type="checkbox"/> Negative <input type="checkbox"/> Unknown <input type="checkbox"/>
Previous other cancer (please tick):	Yes <input type="checkbox"/> No <input type="checkbox"/>
Family history of breast cancer (please tick):	Yes <input type="checkbox"/> No <input type="checkbox"/>
Family history of other cancer (please tick):	Yes <input type="checkbox"/> No <input type="checkbox"/>
Risk-reducing surgery (please tick):	Contralateral <input type="checkbox"/> Bilateral <input type="checkbox"/>

Appendix 9: Hospital Anxiety and Depression Scale

HADS removed for copyright purposes

Appendix 10: Interview Guide (with refinements)

Trust Information Removed



Interview Guide (patients) Patient and surgeon decision-making in risk-reducing mastectomy: an ethical and empirical analysis

Interviews will be at a time convenient for the patient. The interview will be conducted at the hospital, at the patient's home or by telephone as the participant prefers. For consistency, and to ensure that the research questions are addressed, a semi-structured approach will be used, with participants prompted to address specific topics in each interview.

Closed questions will be avoided as much as possible as these constrain the information gained from the participants. For this reason also, interruptions from the interviewer will be kept to a minimum with interviewer dialogue limited to reflecting, prompting and summarising, with open or closed questions and probing where necessary. To avoid generalised responses, participants will be encouraged to speak about their specific experiences as much as possible.

Before the interview commences it is essential to ensure that the patient has read the information sheet, and that they have made a decision and do not plan to revisit it in the next three months.

Questions and prompts below are resources on which the interviewer will draw and only relevant questions should be asked. Questions should not be imposed to disrupt conversational style.

1. Introduction
2. Reassurance of confidentiality (including reassurance that their doctors and nurses and other clinicians will not be told what the participant has said and that their treatment will not be affected by what they say, unless they say something that indicates risk)
3. Clarification of research aims
4. Elicit and answer questions about the interview process and the Patient Information Sheet
- 5.0 The interview questions will be guided by the structure below. The questions are illustrative and the format and sequencing will be guided by the patient's responses.

5.1 Background

At what point did you first consider RRM?

How did you come to consider RRM?

(if patient spontaneously considered RRM) Where did you hear of RRM?

5.2 Decision-making

Could you please describe how you made the decision to have/not have RRM?

How did you feel during decision-making?

What sort of issues did you consider when you were deciding whether you wanted RRM?

Of these, which issues were important to you?

What sort of information did you seek, to help you make that decision?

To what extent did you consider the risk of cancer?

(if so) How high or low did the risk of cancer seem to you?

What factors did you think contribute to risk?

How did you feel about this risk?

} Use similar questions
to ask about other
issues mentioned
(e.g., risk of operation,
cosmetics etc.)

Did you approach anyone to help you to make the decision? Who?

What was the most important contributor to your decision-making?

Elicit information about timeline- e.g. what can first / second?

5.3 Decision process

Which clinical staff did you talk to about your decision?

How did each staff member respond to you?

Who raised the prospect of you having an RRM?

(lower risk CRRM only) Can you tell me when and how you indicated to your surgeon that you were interested in CRRM?

(lower risk CRRM only) How did your surgeon respond when you indicated that you were interested in CRRM?

What did you want to get out of the discussions with your family/doctor/nurse/counsellor?

Did [family/doctor/nurse/counsellor] speak to you about the risks associated with your decision?

Who spoke to you first about the risks associated with your decision?

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

Could you describe how talking to clinical staff or family influenced your decision?

How did the role of worry/emotions/risk shape up your decision?

5.4. Decision satisfaction

How do you feel about your decision now?

When was it clear to you that you wanted this?

What were your thoughts at that time?

What would you (give up) to reduce risk?

6. Does the participant have any questions or any concerns about anything that has been talked about?

Rating risk pre surgery (%) / post surgery (%).

7. Thank participant for taking part.

NOTE: If a patient brings up the following, try to ask for more information on these areas:

“need to get on with life” – how is this stopping you from getting on with your life?

“need to be in control” – what does being in control mean to you?

“want to avoid chemotherapy/mammograms” – how has this influenced your decision for wanting risk-reducing mastectomy?

Italics: Refinements

Appendix 11: Dealing with distress protocol

Dealing with distress

Within the information sheet, participants are informed that they do not have to take part in the study and are free to withdraw at any point without negative consequences for the participant. The researcher will reiterate this information as regularly as is felt necessary.

If a participant becomes distressed during the course of the interview (visually appears distressed or informs the researcher that this is the case), the interview will be paused and the participant will be asked if she wishes to continue, or if she wishes to interrupt or stop the interview and/or if she wishes to discuss her concerns with the researcher.

If the researcher is concerned about the degree of distress, the participant should be encouraged to contact their GP or mental health provider or' with the participant's consent, the researcher will ask a member of the research team to do so. With consent, the researcher will inform the Clinical Psychologist from the Breast Cancer Unit (name) of the distress experienced.

If the researcher is concerned that the participant is at risk of harm, or that someone else is at risk, she will seek her consent to refer these concerns to an appropriate clinician. However, the duty of care would mean that, even if consent were not provided, the researcher would need to make this referral as appropriate.

If the participant feels able and the researcher agrees, the interview will be resumed.

With her consent, the participant will be contacted the following day. The participant will be encouraged to contact the research team if she experiences increased distress in the hours/ days following the interview. Contact numbers for the research team are supplied on the participant information sheet.

If a participant becomes distressed the researcher will record the action taken.

If the participant feels unhappy with the interview process and wishes to complain, the participant will be directed to the contact details for the Customer Relations Team on the participant information sheet.

Appendix 12: Data Protection Protocol

Data Protection

Demographic information will be pseudo-anonymised (to link with interview transcript) and all potentially identifying information will be removed/ replaced with a code. Information will be stored electronically at Liverpool University on a secure password protected computer system. Research team members only will have access to the transcripts during analysis. Following transfer to the computer, raw data (paper files e.g. demographic information) will be stored in the D.Clin.Psychol. office.

Interviews will be recorded on a digital Dictaphone; audio data will be transferred on to a university password protected computer as soon as possible. Following transfer to computer, audio data stored on the Dictaphone will be deleted.

A university recognised transcription service will be responsible for all transcriptions. [Researcher] will be responsible for ensuring that the transcription service employed during the investigation has deleted all electronic copies of the data from their computer hard drives/portable disk drives etc. sent by [Researcher]. When data is part of the wider study and sent for transcription by a member of the wider research team, responsibility for data deletion will fall to the data custodian, [Chief Investigator/ supervisor].

Transcriptions will be pseudo-anonymised with respect to all names of people and places and other potentially identifying information. Transcripts will be stored electronically at Liverpool University on a secure password protected computer system. Research team members only will have access to the transcripts during analysis.

(Trainee) will retain an electronic copy of all transcribed files for her own records until the point of the viva voca examination. Up-to-date copies of all electronic files (relevant to the thesis) will be stored on [Researcher] allocated workspace on the University computer network. Transcribed files will not be kept on any home PC.

Following the viva voca examination, [Trainee] will submit hard data to the D.Clin.Psychol. office for secure destruction by the University Records Management Service.

All the electronic data relating to the thesis will be archived to CD. The CD containing the electronic data and any remaining copies of the raw hard data, such as participant consent forms, will be given to the data custodian [Chief Investigator / supervisor] who will be responsible for data storage. Transcripts will be archived with the Economic and Social Data Service for access by other researchers (data sharing procedures are explained in ESDS (2012) Managing and Sharing Data (p. 23) <http://www.data-archive.ac.uk/media/2894/managingsharing.pdf>). This will be explained to patients and they will be asked to consent to it.

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

It is the responsibility of the data custodian to ensure that all hard and electronic copies of any data files that relate to the major research project at the end of the data retention period have been securely destroyed.

Appendix 13: Data analysis Example Vignette

ID1: This patient was a young mum and had had breast cancer before. She was driven by the anxiety of the cancer returning, reducing her life expectancy and her not being around for her young children. She wanted to have the CRRM and not go through the yearly mammograms and chemotherapy again, which were both horrible experiences. She had an attachment with the surgeon as she has performed the previous surgery wanted to do whatever she could to reduce the risk of getting cancer again.

Appendix 14: Example of summary of analysis meeting

15/04/14

Implications for the interviews – what do women mean by ‘doing everything I can’

- What don't the women do? – at what point do the women think ‘I've done all I can’?
- What else do women do to reduce the risk?
- What else do women feel about the fear –can they quantify the fear? Intensity/constancy (never leaves them)?
- Mammograms = lack of trust / bad experience / does not want to wait for it to come back
- Heterogeneity of fear – fear of lurking ‘thing’ / variation of what they are fearful of / individualised fear / universal fear
- Nature of fear – uniformity of an imposter in one's own body
- Intrinsic fear – social fear – in what to do – availability of information of options
- Only way you know what is reasonable and what can be done is from knowledge that is socially transmitted
- Fear of regret – Is the anticipated regret driving the decision or is it about doing everything they can?
- Logic of decision-making may be either rational or ‘get it out of here’ response – why the difference matters?
- Bad experience –metaphor of cancer
- Vicarious experience

Intense menace

Menacing – rather than inevitability – fits with the fear – something lurking that merits extremes measures

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

- Capacity that the monster that lurks cannot be stopped unless drastic measures are taken – removed from the territory

Risk-reducing

RR is important – only care about where it ends as long as its reducing – not by degree – downwards trajectory – done whatever I can do to reduce the risk – not talking about combinations for reducing the risk

Appendix 15 Example of Initial Analysis (for fear/ vulnerability)

February 2014

Emerging themes	Possible Subthemes	Interview ID and line number	Example Quotes
Fear/worry/anxiety ?	Vulnerability	ID1: 232, 250, 438-439, 444-445, 447, 640, 652-654, 947 ID3: 108-124	<i>"...I suppose I want to live with a little less fear than I live now." (ID1)</i> <i>"Because mine [test results] were triple negative I, it was, the tablets were no use to me because...now I know it's genetic...but I couldn't understand last year. I thought, why are they all on pills for hormones and mine was triple negative? What caused it? Something must have caused it...so I thought I'm feeling vulnerable that if it happened again all I've got to rely on is chemotherapy...which I didn't enjoy going through...I had no protection, so I didn't know up to then what had caused it until my genetic test." ID3</i>
	Perception of existence as dangerous	ID1: 524, 537-538 ID1: 289-293	<i>"I know my life expectancy is going to be less that the other guys who've not had it." (ID1)</i> <i>think, I suppose not would help because you know they can't... nobody's going to say to you, you're free of it. That's it, it's gone... gone. You know, your body can turn bandit at any point, can't it? (ID1)</i>
	Anticipating fear of cancer returning again that was driving her decision	ID1: 190-191, 318, 484-485, 745-747, 788-793, 947-948	<i>"Once you have come to that decision feelings around, um, I don't want this to happen, I don't want this to happen again and actually that was almost more important than perhaps...I don't want it to happen again and I don't want to have...I don't want to find a lump. I don't want to have a mammogram again." (ID1)</i>
	Fear about future motivates her decisions and her emotions in the future	ID1: 302-304, 507-509, 561, 799-800	<i>"...well, there's no alternative. You either have surgery or you don't, or you just change your life, you change everything to give yourself the best chance." (ID1)</i>

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

		<p>ID2: 269-273, 477-478, 766, 771, 787, 815</p> <p>ID3: 412-422</p> <p>ID4: 150</p>	<p><i>"I'm in my late thirties now, my sister and my cousin were diagnosed sort of mid-forties, you know, 46, 45 er early forties you know. Five years from now will take me up to my sister and my cousin's age so, you know...and that's how...I'm a very logical person, I kind of see things in, in stages like that." (ID2)</i></p> <p><i>"Once I have the operation done I'll be so relieved and I'm looking forward to just getting back to normality again. Don't want to go down that road again of going what I went through last year...the chemotherapy was the worst...I didn't like that. It's all the side-effects and everything. It took me a year to get over all the effects from that." (ID3)</i></p> <p><i>"...I want a baby as well...that's an emotional thing I suppose...I want a baby, and everyone's getting pregnant and not me" (ID4)</i></p> <p><i>"I feel I got cancer due to having the baby as well...because it was hormonal and it was ductal...I had milk for nearly three years. I shouldn't have had milk, so I think that's why I developed breast cancer, so if I get rid of the other one and have another baby, then it will be okay."</i></p>
	Emotions for the consequences of her decision to have surgery	ID2: 370-377, 412-414, 441	<i>"But then I found myself. ...stopping and then saying to my husband, oh well actually, that, that's me. It's affecting me." (ID2)</i>
	Managing the worry rather than making the decision	ID1: 454-455	<p><i>"I suppose at this point it's psychological, isn't it, that I don't want to ever find a lump...in my breast again" (ID1)</i></p> <p><i>"The fear is always going to be psychological. I think it's more of a psychological decision that you make." (ID1)</i></p> <p><i>"The fear of, of, of that rather than perhaps weighing up the risk" (ID1)</i></p>

DECISION-MAKING REGARDING RISK-REDUCING OPTIONS IN BREAST CANCER

	Worry of entering the "Danger zone"	<p>ID2: 269-273</p> <p>ID3: 261-267</p>	<p><i>"I'm in my late thirties now, my sister and cousin were diagnosed sort of mid-forties...Five years from now will take me up to my sister and my cousin's age...I'm a very logical person, I kind of see things, in stages like that." (ID2)</i></p> <p><i>"I made that decision the end of last year to the doctors in the hospital, please take them out, I don't want them...I don't want that worry, what I seen what my mum went through. So yeah, I had open surgery in the end of January this year...I had them removed, and my tubes, so, so relieved."</i></p> <p><i>"I feel I got cancer due to having the baby as well...because it was hormonal and it was ductal...I had milk for nearly three years. I shouldn't have had milk, so I think that's why I developed breast cancer, so if I get rid of the other one and have another baby, then it will be okay." (ID4)</i></p>
	Avoiding mammogram and three week test results	<p>ID1: 76-78, 792</p> <p>ID3: after interview the patient added this point that she felt was important</p>	<p><i>"...you have to wait three weeks for that, and I was just sat there thinking, I just don't want to do that." (ID1)</i></p> <p><i>An important reason for the decision to have RRM was to avoid having mammograms again in the future. It wasn't the fact of how uncomfortable they were but more the worry over the 3 weeks whilst waiting for the results. She did not want that every year for the rest of her life and having the surgery meant she would not need to go for the mammograms anymore which were a big factor in her decision to have the RRM. (ID3).</i></p>

Appendix 16: Example data analysis- conceptual categories (Fear)³

1: I want to live with a little less fear: Fear is important in DM

- Women's decisions seem to be driven by fear of cancer returning (?).
- Fear of having to go through treatment again particularly chemotherapy and fear /anxiety following mammograms (hard to know if this is their justification for the decision they have made).
- Fear of dying and leaving their family, particularly young children.
- Women explicitly stating that the decision is driven by fear.
- Fear and worry as 'constant'
- Timeline- initial emotional reaction/ logical process after – where does decision get made?
- Where is fear from? Fear for life? Innate versus socially-mediated fear response
- Cancer as avoiding detection/ lurking and insidious
- Cancer as a hidden 'menace'
- Social processes impacting upon fear? E.g. the 'big C' (less support for this now).
Request to 'get it off' interpreted as request for RRM
- Experience of having breast cancer colours/ impacts upon fear.
- May be heterogeneity in fear – possible that not everyone is frightened of same thing?

³ For full details see data CD